Exploring Discourses on Quality of Health Care: Perceptions among the 'Mang' and 'Maratha' Communities of Nanded District, Maharashtra

Thesis Submitted to Jawaharlal Nehru University in partial fulfilment of the requirements for the award of the degree of

DOCTORATE OF PHILOSOPHY

Ghodajkar Prachinkumar Rajeshrao

Centre of Social Medicine and Community Health

School of Social Sciences

Jawaharlal Nehru University

New Delhi

2022

Centre for Social Medicine and Community Health

School of Social Sciences,

Jawaharlal Nehru University, New Delhi

Declaration

Date:30/12/2022

This is to certify that the dissertation/thesis entitled **Exploring Discourses on Quality of Health Care: Perceptions among the 'Mang' and 'Maratha' Communities of Nanded District, Maharashtra** submitted by **Dr. Ghodajkar Prachinkumar Rajeshrao** in partial fulfillment of the requirements for award of degree of Ph.D. of Jawaharlal Nehru University, New Delhi, has not been previously submitted in part or in full for any other degree of this university or any other university/institution.

Ghodajkar Prachinkumar Rajeshrao

We recommend this thesis be placed before the examiners for evaluation for the award of the degree of Ph.D.

Signature of Supervisor

Prof. Ritu Priya Mehrotra

Date: 30th December 2022

Signature of Dean/Chairperson

Prof. Rama V Baru

Date: 30th December 2022

Acknowledgement

It took me very long time to write this thesis. Finally, this phase is coming to an end. The entire journey of this research from its conception and reading for it, doing data collection was very interesting and exciting. The data analysis and putting chapters together was long drawn process with no one other than me to blame. However, this long journey gave me an opportunity to take inputs from various sources and think about my work. I take an opportunity express my gratitude to all those who helped me reach here.

I am indebted to my teacher and PhD supervisor, Prof. Ritu Priya, for helping and guiding me not just in writing this thesis but also for initiating my journey to understand public health. I will be forever indebted to her efforts in making me understand the importance of 'public' also in Public Health. I wish to learn some qualities like kindness, patience and hard work that she bestowed upon me. My words fall short to acknowledge her efforts teaching me balanced perspectives in Public Health.

I take this opportunity also to express my gratitude to all my teachers in CSMCH for being accommodative, encouraging and supporting during this entire journey. I also sincerely express my thanks to all the staff members from library and office for timely help on numerous occasions.

My research would not have been possible without the help of affectionate people of Panshevadi village who hosted me and helped me learn about health, health services and various other issues. I sincerely thank my friends from Panshevadi, Jayram More, Dhanraj More and Ganpat More who were my source of support and strength during my stay in the village. Thank you for making space for me your lives.

I take this opportunity to express my gratitude to Chris for making this work readable by doing tedious editing work in very short time. Thanks to Krishna, who kept me focused in writing process, taught me new techniques useful in research writing and helped formatting. I am very thankful to my friends, Garima, Ayesha, Pradeep, Kamalini, Arun and Honika for their help in writing process. Thanks to Milind, Jomo, Lakshmi and Ketaki for being round and the invaluable support.

It is usually said that giving up is simply not an option when you have a supporting family. I am truly blessed and thankful to all the members of my family, both by blood and by law, for their wishes and support in completion of my thesis. My humble gratitude to parents and siblings for their continuous efforts to make me complete this work, this research would not have been possible for me without their support.

Finally, thanks to the most significant anchors of my life, my partner Jayashree, who primarily faced the brunt of my long drawn thesis writing with patience.

Lastly, I own all the responsibility of the theoretical flaws and incongruity of ideas in this thesis.

-Prachin

Contents

List of Tables

List of Figures

Abbreviations

ACSQHC	Australian Commission on Safety and Quality in Health Care
AHCPR	Agency for Health Care Policy and Research
ANC	Anti Natal Care
ANM	Auxiliary Nurse and midwife.
AYUSH	Ayurveda, Yoga and Naturopathy, Unani, Siddha and Homeopathy
CABG	Coronary Artery Bypass Graft
CCHSA	Cabarrus County Home School Association
CHC	Community Health Centre
CHF	Congestive Heart Failure
CHW	Community Health Workers
CMO	Chief Medical Officer
COE	Council of Europe
DHO	District Health Officer
EC	European Commission
ECHI	European Core Health Indicators.
FNAC	*Fine needle aspiration cytology*
FP	Family Planning
GP	General Practitioners
HCQI	Health Care Quality Improvement
HDI	Human Development Index.
HEDIS	Health Employer Data Information Set
HSR	Health Systems Research
IOM	Institute of Medicine
IMR	Infant Mortality Rate
IPD	In-Patients Department
ISO	Interactional Standardized Organization
JCAH	Joint Commission on Accreditation of Hospital
JCAHO	Joint Commission on Accreditation of Healthcare Organizations
JSY	Janani Suraksha Yojana

LHS	Learning health systems
LHV	Leady Health Visitor
MCH	Maternal and Child Health
MPW	Multipurpose Health Worker
NHPAC	National Health Priority Action Council
NHPC	National Health Performance Committee
NHS	National Health Service
NICE	National Institute for Clinical Excellence
OECD	Organisation for Economic Cooperation and Development
OPC	Organo Phosphorus Compounds
OPD	Out-Patient Department
PAF	Performance Assessment Framework
PDSA	Plan Do Study Act
PHC	Primary health Care
PI	Performance Indicators
PNC	Post Natal Care
PREM	Patient Rated Experience Measures
PRO	Peer review Organization
PROM	Patient Rated Outcome Measures
PSRO	Professional Standards review organization
RCH	Reproductive and Child Health
RH	Rural hospital
SDH	Sub District hospital
THO	Taluka Health Officer
TQA	Total Quality Assurance
TQM	Total Quality Management
TT	Tetanus-Toxoid
WHO	World Health Organization
ZP	Zilla Parishad

Introduction

Globally as well as in India there is a growing demand for improving the quality of health service from patients, insurers, regulators, and accrediting organizations. In the present time, the goals and objectives of quality are pursued through accreditation of health care institutions. The accreditation of Apollo hospital in Delhi by the Joint Commission for Accreditation of Healthcare Organizations (JCAHO) (The Hindu, 2005) set off this trend in India and many hospitals are now following suit, queuing up to have their credibility vouched for by different national and international bodies accrediting medical care institutions. To understand and respond to this growth in demand for quality in health care service delivery, it is necessary to examine the meanings of quality. Unfortunately, there is lack of consensus on the meaning, definition and subject matter of quality in health services.

In popular imagination in India, 'quality health care' is associated with services provided in luxurious private hospitals like Apollo, Escorts, Jaslok, Leelavati, etc. located mostly in metropolises. 'Quality health care' immediately summons associations of high costs and its un-affordability for ordinary people. The healthcare professionals' and establishment's notion of quality emphasizes technical excellence, i.e., how well they comply with the latest technological prescriptions. High technology is deemed synonymous with good quality services (Roemer et al., 1988).

Another common understanding is that quality is dependent on health workers, and it is presumed that quality of care can be guaranteed by the presence of 'specialist' healthcare professionals. This is reflected in the Supreme Court judgment of the year 2005 allowing only gynecologists having MD/DGO or doctors with a minimum of five years of experience in gynecology to perform family planning (Tubal Ligation) operations (Rao, 2005). This decision however, is likely to result in inaccessibility of family planning services for the majority in rural areas, because of the concentration of specialist services and providers in cities and district headquarters in most of India. Hence, it is important to reckon with the fact that the definition and criteria of quality cannot be divorced from the 'objectives' of care and the purpose for which the quality is being examined.

Al-Assaf (A.F., 2001) lists reasons underlining the importance of examining and defining the notion of quality based on the objectives:

- The increased demand for improvement of care, appropriate care, effective services.
- The need for standardization and variance control.
- The necessity of cost saving,
- Benchmarking, accreditation, certification and regulations, report cards on provider performance.
- Defining and meeting patients' needs and expectations.
- Enhancing marketing and competition.
- Meeting the desire for recognition and striving for excellence.
- Ethical considerations.

The shift towards purchasing, rather than funding, health services has resulted in attention being given in many countries to ways of measuring hospital performance and, within this, to measuring the quality of hospital care (Draper & Hill, 1996). Report cards on services are an outcome of this shift. As governments and societies pay more attention to health service quality, a more explicit understanding of the concepts of health care and quality of care are required. Different understandings of quality will lead to different policy paths, strategies, and active measures for its improvement.

The state's active pursuit of quality improvement programs for health services in the present, is simultaneous with its consistent attempt to withdraw from health service delivery, as part of its implementation of neo-liberal economic policies, that negatively impact welfare and income of vulnerable groups and hence their access to healthcare services. This contradiction makes it imperative to understand how quality is defined and improved in the health services. It also raises the question, the ways in which the criteria for quality of health services will contribute to the health of the population, especially vulnerable groups.

The scope and composition of the concept of 'quality' in healthcare has undergone change over time. Different countries, healthcare organizations have pursued different definitions through

different systematic intiatives for quality assessment, accreditation, assurance and improvement. The goals and subject matter of these quality intiatives also have differed across time and place.

Much of the quality related interventions in health are operational at the level of healthcare service institutions. Some of these quality related interventions are applicable to health service systems. The dimensions of quality chosen for interventions have influence on scope and limitation of related programatic interventions. The dimensions of quality seen as relevant by health policy leaders, healthcare professionals, payers and insurers and the patients are different.

In the contemporary time with emerging approaches of coproduction and Learning Health systems (LHS) it becomes imperative to engage patients, families and communities, especially vulnerable groups, in deciding the structure, design and objectives of health service systems along with the quality of services provided through the health service system. Examination of care-seeking journeys is useful in understanding what are the user community's experiences with and expectations of quality from health services and service systems. This study attempts to explore community perceptions of quality in health care among 'Mang' and 'Maratha' communities of Nanded district in Maharashtra.

The first chapter discusses different definition and conceptual underpinning of the 'quality' in health care. This chapter also discusses conceptualization of research problem and methodology adopted to study community perceptions of quality in healthcare. The study of what constitutes 'quality' in health care for people could be studied through patient feedback and/or opinion surveys or their responses to hypothetical scenarios. However, recognizing the limitations of these methods for capturing the effective perception of people that guide their actions, especially for whole multi-level health care system rather than only single institutions or even hospital chains, for this study we decided to capture perceptions of quality through people's reflections on the experience of various phases of their healthcare seeking journeys.

The second chapter explores the discourse on quality of healthcare. It discusses important frameworks used by different organizations and countries to assess and improve quality. The issues relevant for quality assessment along with scope and limitations of different indicators of quality are also discussed. Examining the evidence on differential quality of services given to different community groups, the social determinants of quality have been highlighted making a

case for studying different community groups in assessment of community perceptions of quality.

Chapter three begins discussing community perceptions. The first step in care seeking journey is making a decision of seeking care, contemplating on choice of care providers. The choice of care providers and thinking that goes behind it brings out some factors that are important for understanding quality. Along with the choice of care provides this chapter also discusses the overall experience of care seeking for the community to ascertain the factors highlighted by them as relevant for understanding quality.

The fourth chapter puts together the factors relevant for quality from their experience and expectations that operate at the level of institutional structures and processes. The factors relevant to quality based on their reflections on clinical or medical care given are discussed in chapter five. Chapter six discusses the experiences related to therapeutic, nursing and support services to understand how they are relevant for understanding quality.

Chapter seven analyses their responses on issues such as opinion on cost of care that they had to incur how people compare services provided in public and private sector in terms of quality. Social distance of the care providers and institutions as also experience of discriminations in health care settings, are also covered as they were reported as important elements for quality in health care. The community members had some suggestions for making their care seeking experience better and for improving quality services, and these also have been discussed in this chapter.

The final chapter presents a summary and discusses the relevance of community perceptions in relation to the larger discourse of health systems development as well as quality of healthcare. It also highlights the importance of the methodological approach of using care-seeking journey to study community perceptions.

Chapter-1 Conceptual Underpinnings of 'Quality' in Health Care: Care-Seeking Journeys to Study Community Perceptions

1.1 What is Quality?

Much of the literature on quality originated in manufacturing sector and management studies, meant for the industrial sector (Andaleeb, 2001). We have an intuitive understanding of the meaning of quality, yet when one sets out to study it, the concept and its application become very elusive, given the multifaceted nature of quality. It is important to understand the concepts of quality before attempting to implement quality improvement initiatives in our daily work. Many efforts to improve quality are likely to degenerate or fail, because of the failure to understand its multi-dimensional nature. It is important to accept that quality is best defined and applied in the context of a specific time, space and activity (Hock, 2005)

Most common endeavours of quality improvement, begin with a set of standards and checks are then made to see if the products meet the stipulated standards and requirements. This would then result in acceptance or rejection. Though rejection is wasteful, the raw materials of the rejected goods can be used again. Minor repairs and modification may make a rejected product meet the standards. Likewise, in the process of quality improvements, it may be discovered or decided that the standards are inappropriate and need to be changed.

Unlike goods, bad services once rendered to a customer cannot be withdrawn. Hence, the objective should be to remedy the bad outcome and to improve the next service encounter. In addition, service quality is an abstract and elusive construct because of some features unique to services: intangibility, heterogeneity, and inseparability of production and consumption (Parasuraman et al., 1985).

1.2 Definitions of quality /Different views on quality

The dictionary meaning of the word quality refers to "an essential distinguishing attribute of someone or something" or "a degree or grade of excellence or worth"[1]. The International Organization for Standardization defines quality as "the totality of features and characteristics of products or services that bear upon its ability to satisfy stated or implied needs."

[1] (www.wordreference.com/definition/quality)

Listed below are some of the important definitions of quality put together by Al-Assaf (A.F., 2001). While most of those mentioned below incorporate the criteria of 'objective specification' and 'customer satisfaction', others dwell on innovations, minimizing of defective products and still others emphasize its procedural aspects while including the element of incremental improvement.

- Quality is conformance to requirements or specifications (Philip Crosby, 1978 cited in A.F., 2001).
- Quality is meeting the requirements of customers, both external and internal, for defect free product and services. (IBM, 1982, cited in A.F., 2001).
- Quality is providing customers with innovative products and services that fully satisfy their requirements. (Xerox, 1983, cited in A.F., 2001).
- Quality is the degree to which care services influence the probability of optimal outcome (American Medical Association, 1991 cited in A.F., 2001).
- Quality means simply meeting the customers' requirements, the most widespread definition in commerce and industry (Oakland, 93 cited in A.F., 2001).
- Quality is doing the right things right the first time and doing it better next. (Al Assaf, 1993, cited in A.F., 2001)
- Quality is the process of meeting the needs and expectations of customers, both internal and external. quality can also be referred to as a continuous process of incremental improvement (Al Assaf, 1998, cited in A.F., 2001)

Beyond these basic concepts of 'making things better', quality becomes a much more complicated undertaking.

There is a relatively long history of quality evaluation in industry, particularly within the manufacturing sector. Distinct approaches to quality can be identified which are inextricably linked to underlying methods of managing organizations, work, and people. Three different models of quality evaluation have been suggested by Gill Harvey (Harvey, 1996). These models

are as follows: quality as the responsibility of individuals; quality as an exercise in inspection; and quality as a means of continuous improvement.

1.3 Approaches to Quality:

The definition of quality takes on a new meaning, depending on the approach taken to attain it. Gravin DA (Garvin, 1988) suggests five main approaches to attain quality-transcendent, product-based, user-based, manufacturing-based and value-based

Transcendent: This philosophical approach defines quality as something absolute and universal. Quality is perceived as something experiential that cannot be resolved into measurable dimensions. Unfortunately, this definition is probably the least practical.

Product-based: Almost diametrically opposite to the transcendental approach, the product-based approach is only concerned about the most tangible aspects of quality. Quality is seen as being only what is measurable in a product. Differences in quality are represented by differences in ingredients, components, and attributes. This approach is very attractive as it appears to be objective and precise. However, there are severe limitations to this approach as it does not take into consideration the less tangible aspects of quality such as cultural preferences, aesthetics, and individual taste.

Manufacturing-based: This approach sees quality from the perspective of the supplier or service provider. Designs or specifications that are assumed to represent high quality are laid down. Conformance means quality and deviation means reduction in quality. This approach is attractive to policy makers, engineers and designers as it simplifies matters into specifications and control of deviation.

However, it raises the issue of the role of experts in standard setting. Thus, a limitation of this approach is that the environment/ context, customers, and users become peripheral. It is an inward-looking approach that often results in products and services that are perfect from the provider’s point of view, but are rejected by the market and the customer as irrelevant or of low utility.

Value-based: Central to this approach is the concept of 'value for money'. Quality is defined in terms of conformance to costs and prices. With the rise of consumerism and the ease of obtaining information, price comparison is a major factor to be considered when comparing quality of products and services. Cost-conscious third-party payers and purchasers of healthcare services are naturally the most avid proponents of this approach to quality. Affordability becomes an important determinant of quality. Product features and engineering reliability become irrelevant when a product or service is seen as unaffordable.

User-based: This customer-centered approach defines quality from the individual user's perspective. High quality means greater satisfaction of the needs and wants of the user. This approach is appealing to the service providers and advocates of quality management. The International Organization for Standardization's ISO 9000 states "the standardized definition of quality refers to all those features of a product (or service) which are required by the customer" (www. iso.org).

However, in a complex healthcare sector with hegemony and power of medical professionals over knowledge on the one hand and patients whose knowledge is limited on the other, one can encounter situations where wants and needs may be divergent. The purchaser (insurers) and user (patients) may also have dissimilar needs and thus have conflicting definitions of quality. Something of high quality therefore is one that best meets the needs of most of the users, most of the time.

The limitation of measuring quality by consensus is obvious when individuals with their unique needs and wants encounter products and services that are created for the greater good of the majority.

These different approaches may be contradictory in their final assessment of quality. Their validity depends on the approach that is most appropriate for a particular situation or activity. Therefore, (Hock, 2005) suggests the need of a sixth approach for defining quality and that is the contextual approach or a context-based approach to quality. Each of the earlier five approaches given is used to create a composite definition that is contextually appropriate.

In an ideal market setting or transaction, the consumer knows or is informed about what goods or services s/he is buying along with its utility and judging its quality requires relatively good information. However, when consuming health care, patients often don't know what is wrong with them- the underlying disease condition, what treatment options are available, what the effectiveness of care might be. Often, they can neither judge the quality of treatment before the event and very often, nor afterwards. Health care is highly complex and technically advanced and usually very little information is shared with the patient. In this context of information asymmetry, we cannot leave health care and its quality assessment to the market. So then who is to judge quality?

Different stakeholders (users, clinicians, payers) have different definitions and views on quality of care. The view of quality of care under certain circumstances is determined by accessibility and effectiveness, and in other circumstances view of quality would be shaped by the expectation of service process or outcomes. For example, the management cares about efficiency and profits on costs incurred, while the users would be more concerned with whether the services provided were patient-centered and met individual needs (Yang, 2007).

1.4 Quality in health care

Research funding and activities have focused on understanding disease mechanisms and identifying new effective therapies. However, very few studies have investigated methods of delivering these treatments safely, effectively, efficiently and with low cost. Some of the greatest opportunities to improve patient outcomes will probably come, not from discovering new therapies, but from devising more effective ways of delivering existing therapies (Pronovost et al., 2004).

When assessing quality in healthcare the structure, process, and outcomes of care must be examined. Donabedian (Donabedian, 1966) suggests a three-dimensional analysis of health services: the structure of health services, the process of actual services provided and the interactive outcomes of the system.

1.4.1 Donabedian's framework of Quality

Health services structure

Health services structure is the organizational factor in the health care system, including physical and human characteristics. The physical characteristics consist of the hardware such as equipment and facilities, also the software such as regulations and regimes, and the 'physical body' such as the number, specializations and structure of the workforce. The structural capacity of the healthcare system is the cumulative of the resources and relationships necessary to facilitate the provisions of health care (Handler et al., 2001)

The attributes/ constituents of structural factors include man, money and material. Human resources consist of the number and qualifications of personnel. Financial resources in a sufficient quantity at the required time are an important prerequisite for providing health care. Material resources include facilities, equipment, drugs and instruments etc. In addition to this, organization of these resources in terms of staffing pattern, organization of preventive, promotive, curative and rehabilitative services is also an important structural element.

Therefore, an assessment of structure is a judgment of whether the conditions or settings in which care is being provided are conducive to supplying good care (Mainz, 2003). Conditions conducive to good care call for adequate facilities and equipment, qualifications of the medical staff and their organization, the administrative structure and the operations of programs and institutions providing care (Donabedian, 1966). Structural assessment also involves the study of system factors such as staffing patterns, and characteristics of care providers (Lee & Mills, 2000).Variables considered in a measure of structure may describe the physical environment, organizational resources, or the training, experience, and specialization of providers (Birkmeyer et al., 2004; Donabedian, 1985; Handler et al., 2001). The structural factors of health services provide conditions and settings where there is a possibility for individuals to access health care services, but it does not mean that the individuals are actually able to obtain necessary and quality health services. Thus, structural factors and attributes though indirect measures of the quality of care, help identify where the quality is likely to be lacking (Donabedian, 1985) which is important to initiate quality improvement measures.

Health service process

'Process' refers to what is actually done in giving and receiving care, it encompasses a series of interrelated activities undertaken to achieve objectives of health care intervention i.e. the practitioner's activities in diagnosing, recommending or implementing treatment, and other interactions with the patient. 'Process' refers to the actual delivery of care from the point a person enters the health care system to the point where he or she is restored to health or is beyond further treatment. Other important components of health service processes are administrative, logistical and the provision of technical support. Process also includes activities such as home care, health promotion, community support and health education (Hock, 2005). Process therefore encompasses the totality of patient care activities.

The interaction between health care providers and end-users, or the offer of and access to health care services is also a part of the health service delivery process. Assessment of process involves the study of what the care provider does as well as describes the care that patients need and eventually receive. Some authors include the patient's activities in seeking care in their definition of the health care process while others limit this term to care that health care providers give (Mainz, 2003).

Many researches show that there are two types of interactions; clinical service and inter-personal service (Yang, 2007). Clinical service refers to the application of clinical/ medical techniques to solve personal health problems e.g. an assessment of the application of medical knowledge and degree of adherence to the standard treatment protocol (Donabedian, 1966). There are standard formulas to assess the quality of clinical or technical services, with assessment principles of suitability and necessity to gauge extent of overuse, under-use, and misuse of resources (Yang, 2007).

Inter-personal service refers to the sociological and psychological interactions between the service providers, caregivers, and users. The skills for inter-personal care include communication skills, the capacity to build mutual trust, the ability to understand and to be with the patients, sensitivity and the capacity to respond to the patients' request. Efforts to assess processes often focus on the patient's exposure to medical interventions, thereby connecting the process of care to patient outcomes.

Health service outcomes

Health service outcome refers to the direct or indirect effect of the health services structures and processes. Outcome, a self-explanatory term, is essentially the end result of the care process and can be studied and defined in many different ways. Outcomes may range from changes in levels of morbidity, functionality, health status, patient comfort, quality of life, life expectancy to mortality. Improvements in the patient's knowledge and salutary changes in their behaviour may be included under a broad definition of outcome, and so may represent the degree of the patient's satisfaction with care. Cost of care to the patient or to the provider or purchaser is also one of the important outcomes of health care services.

Outcomes can be expressed as 'the five Ds'(Mainz, 2003); (i) death: a bad outcome if untimely; (ii) disease: symptoms, physical signs, and laboratory abnormalities; (iii) discomfort: symptoms such as pain, nausea, or dyspnea; (iv) disability: impaired ability connected to usual activities at home, work, or in recreation; and (v) dissatisfaction: emotional reactions to disease and its care, such as sadness and anger.

The effectiveness of outcome can be assessed in two ways: the assessment by the provider and the assessment by the user (Yang, 2007). The assessment by the provider (also referred to as professional assessment) is the standardized measurement of the physical and psychological state of the patient, which is the objective judgment of the health service outcome from the viewpoint of a clinical expert or researcher. The assessment by the user is the subjective judgment of the outcome by the service user according to his or her own experience while balancing the anticipation of the service, which will affect his or her future medical behaviour.

Outcomes can be used to provide valuable information about the overall performance of the healthcare system. Outcomes are seldom fallible, thus, as concrete measures of health care, outcomes serve as validators of the effectiveness and quality of care. However, while outcomes may imply good or inadequate care, they alone do not point to the nature and location of deficiencies or strengths of the system (Donabedian, 1966).

When measuring the quality of care by analyzing structure, process and outcome of a health service, the significance of each of these aspects could vary depending on circumstances. If the

purpose of measurement is to improve the operation of the health service system, then process is a better index, as it is universal and under the control of health care professionals, whereas, if the purpose of measurement is to assess the contribution of the health services system to individuals or society as a whole, then the outcome index would be more relevant (Yang, 2007).

Donabedian (Donabedian, 1966) in his definition of quality has emphasized on all three components of the health service system i.e. structure, process and outcome. He not only concentrated on the technical domain consisting of infrastructure, knowledge, and skill of a provider, but also on the interpersonal relationship between patient and caregiver. This definition was the first to take the patient's perspective into consideration while assessing quality.

1.5 Important definitions and frameworks of quality in healthcare

The literature available on quality of healthcare shows various definitions in use. Some of the important definitions or constructs of quality in health care that have been influential include construct and definition of quality by Donabedian of the year 1980, Institute of Medicine's (IOM) definition of quality of 1990, Council of Europe's definition of 1997, European Commission's definition of 2010 and WHO's definition of 2018.

Ali Mohammad Mosadeghrad put together some of the commonly referred definitions of quality as *Donabedian defined healthcare quality as "the application of medical science and technology in a manner that maximises its benefit to health without correspondingly increasing the risk. Ovretveit defines quality care as the 'provision of care that exceeds patient expectations and achieves the highest possible clinical outcomes with the resources available". According to Schuster et al. good healthcare quality means "providing patients with appropriate services in a technically competent manner, with good communication, shared decision making and cultural sensitivity."Leebov and colleagues (2003) believe that quality in healthcare means "doing the right things right and making continuous improvements, obtaining the best possible clinical outcome, satisfying all customers, retaining talented staff and maintaining sound financial performance". For Lohr, quality is "the degree to which healthcare services for individuals and population increases the likelihood of desired healthcare outcomes and is consistent with the current professional knowledge"*(Mosadeghrad, 2012). This list is not extensive or all encompassing.

Avedis Donabedian's framework of quality in healthcare is widely recognized and among the most discussed in available literature. Over time, Donabedian's own framing of quality in healthcare underwent some changes. Donabedian (Donabedian, 1980) defines 'Quality care is the kind of care which is expected to maximize an inclusive measure of patient welfare, after one has taken account of the balance of expected gains and losses that attend the process of care in all its parts'. He conveys that quality of care is related to the process of care in all its parts and that the goal of high-quality care is to maximize patient welfare. Patient welfare certainly includes the health status comprising physical, physiological and psychological dimensions. 'Patient welfare takes into account patients' expectations and what patients find important. Gains and losses are expected in the process of care and are recognized in this definition underscoring limitations of health and its quality.

According to the Institute of Medicine (Institute of Medicine, 1990) 'quality of care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge'.

Evans et al. note that, '*the IOM narrowed the goal from improving total patients welfare to improving health outcomes, but also moved the focus from patients to individuals and populations, thus allowing quality of care to incorporate promotion and prevention and not just cure and rehabilitation. It also added two qualifiers: 'desired health outcomes', to emphasize the need to consider the perspective of the recipient of the service*'(Evans et al., 2001 P- 442). The IOM elaborated that these 'desired health outcomes' were expected to reflect patient satisfaction and well-being next to broad health status or quality-of-life measures. The IOM's definition has inspired the understanding of quality among many other organizations in the USA and internationally (Busse et al., 2019).

The IOM also differed from Donabedian on the issue of treatment of resource constraints. Donabedian's initial definition privileged what was maximally feasible for the patient given the current medical knowledge. Subsequently he allowed for an individualized or socially optimal definition, incorporating the concept of value so that quality was the maximum possible for the inputs available. The IOM explicitly rejected the inclusion of resource constraints in the

definition, on the grounds that it should not fluctuate just because resources are constrained and unavailable (Evans et al., 2001 P-443).

The definition of quality becomes narrower or more expansive, depending upon how narrowly or broadly we define the concept of health and the responsibility for it (Donabedian, 1988). The assessment of health care performance will vary depending on whether system's or individual physician's responsibility is limited to improvements in specific aspects of the patient's physical or physiological function or psychological and social functions as well.

Thus, the IOM definition incorporates outcome and processes, two of Donabedian's three elements in a broad approach to assess health care quality. IOM has further suggested some elements for quality of care, which include that healthcare should be safe, patient-centred, timely, efficient and equitable. Aims of effectiveness and safety are nearly universal whereas different societies and cultures differ in the emphasis they give on additional aims of patient centeredness, timeliness, efficiency and equity.

Council of Europe (CoE, 1997) defines, "quality of care is the degree to which the treatment dispensed increases the patient's chances of achieving the desired results and diminishes the chances of undesirable results, having regard to the current state of knowledge". This is one of the key definitions to explicitly include considerations about the aspect of patient safety. This definition was developed to guide the development of quality improvement systems so it prioritizes the assessment of the process of care as an element of quality over accessibility, efficacy, efficiency and patient satisfaction (Busse et al., 2019).

European Commission (EC, 2010) defines good quality healthcare as, "health care that is effective, safe and responds to the needs and preference of patients". While the definition given is brief, the discussion on quality that followed however, invokes other dimensions like efficiency, access and equity and debate over inclusion of these dimensions as part of quality.

World Health Organization (WHO, 2018) in its 'Handbook for national quality policy and strategy 'states that quality health services should be effective (providing evidence-based health care services to those who need them), safe (avoiding harm to people for whom the care is intended) and people-centered (providing care that responds to individual preferences needs and

values. In further discussion other attributes of health services like timely services, equitable services, integrated and efficient services have been invoked.

According to Ovretveit (Ovretveit, 1992) quality in health care means a service "which gives people what they need, as well as what they want at the lowest possible cost."

These definitions show that the discussions on the functioning of health services bring up three concepts - access, cost and quality (A.F., 2001). Access to responsive health services is an important aspect of delivering health services and is a constituent of the concept of quality. The concept of access involves physical, financial, social, and cultural components.

Penchansky Roy and J. William Thomas (Penchansky & Thomas, 1981) propose a broader concept of 'access' comprising dimensions specifically in relation to quality of healthcare. 'Access' encompasses aspects of availability, affordability, accessibility, accommodation, and acceptability, that collectively comprise a major part of what is needed to ensure quality of care. All these dimensions have implications for equity.

• *Availability* refers to the physical existence and sufficiency of needed services. In marginalized areas, resource poor settings, health services are few and the services they provide are meager.

• *Affordability* is the client's ability to pay for services, and includes free services and various forms of coverage. Affordability gains salience in the current context of health care reform- that emphasizes on cost recovery, reduced government provision of services and encourages privatization of health care resulting in implications for equity.

• *Accessibility* addresses location of population and services, transportation, and opportunity costs entailed in using health care services. e.g. the long distances travelled and time spent to get to services, by rural populations, especially those in remote areas, have long been recognized as impediments to health care seeking. Women, with their responsibilities for child care and household chores find it difficult to leave home, or work if they also have wage-earning activities. Often certain, social and cultural practices may restrict women's mobility during the day, further limiting their access to health care.

• *Accommodation* measures a service's adjustment to the time and communication needs of clients. Health workers have greater control over this aspect of quality, as compared to others, within the health facility. Accommodation is also a critical determinant, that shapes the clients' experience and their perception of the health service facility and its responsiveness to their needs. This perception can thus affect all the other components of access depending on how the clients are made to feel.

• *Acceptability* indicates a fit between the service configuration and the individual client and/or community. The health services ability to recognize socially patterned behaviours, for instance, gender-based discrimination in intra-household allocation of resources (food, education, financial resources) disadvantaging women and girls, will be important in shaping strategies to minimize the consequences of these barriers to women's health. Improvements in accommodation of differentiated needs increase service acceptability, alongside improvements in affordability and accessibility.

Even if services are made available, accessible and affordable, they may not be utilized by consumers if they are not acceptable. Hence, the quality of services is an important issue and should be seen from the perspective of patients as well. Quality is achieved when accessible services are provided in accordance with sound professional knowledge in a cost-effective and acceptable manner, as well as when needs and expectations of patients and consumers are met. Hence, while delivering health services the issues of cost, access, and quality are interdependent and complementary to each other.

Maxwell (Maxwell, 1984) defines quality in terms of access to services, relevance to need (for the whole community), effectiveness (for individual patients), equity (fairness), social acceptability, efficiency, and economy.

This definition by Maxwell while listing dimensions of quality like many others, also suggests that the relative weight and importance given to these dimensions will be context and situation-specific. The American Medical Association defines quality of care as "the possibility of enhancing the health services provided to individuals and society based on existing health care professional knowledge, to the expected health conditions." Several definitions and frameworks of quality use idealized vocabulary such as "zero defect", "satisfy expectation", "excellent", etc.,

that may be difficult to operationalize (Yang, 2007). Therefore, a trade-off, striking a balance between scientific objectivity and feasibility is important.

Baru and Kurian (Baru & Kurien, 2002) presented an expanded conceptualization of quality from a public health perspective, which is based on the principles of universality, equity and comprehensiveness. They argue that it is necessary to ensure that quality services are available, accessible and responsive to the felt-need of different sections of the population. To ensure this inclusiveness, they divide dimensions of quality into tangible and intangible categories.

Tangible dimensions include location of health services and their availability, accessibility, affordability to the population being served. In addition, they include the availability of infrastructure, medicines, manpower, transport facilities, financial resources available, distance and cost of health care.

Intangible dimensions include:

- Functional quality- manner of services delivery i.e. issues like time taken, queues, organization of services, administrative procedures involved.
- Technical quality- effectiveness and comprehensiveness of care.
- Interactive quality- includes reliability, responsiveness, assurance and empathy from the caregiver.
- Corporate quality- refers to socio economic and cultural access (issues like caste, class, gender, which impinge upon utilization of services) to health institutions.

Baru and Kurian argue that tangible and intangible dimensions of quality of care are interdependent and interlinked and affect users' perceptions of quality. Their work suggests that people place a great deal of importance on how they are spoken to and treated by medical and paramedical personnel when they seek treatment. This intangible dimension- of the interpersonal relationship between health functionaries and users, is dependent upon a number of factors in society and in the organizations within which these health workers are employed. Hence, they

recommend the inclusion of these dimensions in the medical curriculum so as to have a systemic bearing on quality care.

According to M.I. Roemer and C. Montoya-Aguilar (Roemer et al., 1988) quality signifies proper performance (according to standards) of interventions that are known to be safe, that are affordable for the society in question, and that have the ability to produce an impact on mortality, morbidity, disability, and malnutrition.

1.6 Healthcare Quality Constructs with User/Patient's Perspectives

Donabedian distinguished three components of quality healthcare: technical quality, interpersonal quality, and quality of amenities. Technical quality is the effectiveness of care in producing achievable health gains. Interpersonal quality is about the extent to which patient's needs and preferences are accommodated. Amenities refer to features such as physical surroundings and the comfort they offer along with the organization of available services and provisions (Donabedian, 1980).

Joss and Kogan (Joss & Kogan, 1995), see the concept of quality in terms of three ways: technical, systemic and generic quality. Technical quality is concerned with the professional content of work within a given area. Systemic quality refers to the quality of the robustness of systems and processes that operate for different areas of work. Generic quality comprises those aspects of quality which involve inter-personal relationships between providers and recipients of health care services.

For improving the quality of healthcare, Ovretveit (Ovretveit, 1992) developed a systemic framework based on three aspects viz. professionals, client and management quality. Professional quality is assessed by professionals and it includes their views of whether and how needs of patients (assessed professionally) have been met using scientifically correct techniques and procedures. Client quality refers to the assessment of the extent to which felt needs of patients or users of healthcare services are met. Management quality is concerned with ensuring that services are delivered in an efficient manner, maximizing the benefits of resources invested.

Gronroos (Grönroos, 1984) gives two types of service quality: technical and functional quality. Technical quality refers to the delivery of the core service and its outcome (i.e., what is offered and received). Functional quality refers to the process of service delivery, that is the way in which the patient receives the service. Thus it involves understanding quality by studying how the service is offered and received.

1.7 Quality in Healthcare and different Levels

M.I. Roemer and C. Montoya-Aguilar have analyzed the concept of quality of health care at two levels. First, at a more general level, where resources or inputs, processes and outcomes of health care are involved, quality becomes an attribute of the system as a whole, in all its aspects. When appraising the quality of the health care system in the context of an individual it is natural to take into account the results of such care. However, when judging the quality of health care from the point of view of the population, what matters most in terms of health are changes in survival, morbidity, disability, etc.

At a more restricted level, quality is considered, one of the features of health care resources and processes and is the assessment of compliance with established standards. The attributes of a given set of resources include: their category or type, their quantity, their unit cost and their quality. The attributes of a set of processes include: their type, quantity, effectiveness with regards to the health problems addressed, coverage of target population, and quality. In this perspective, the outcomes or effects of the system would depend on the attributes of the resources and processes including their quality.

YangHui (Yang, 2007) suggests different definitions of quality at different levels, viz. one at an individual level and another at a population level and these are discussed below.

1.7.1 The definition of quality of care to individuals:

High quality service means conditions where one has the “ability to see the doctors and get care and treatment for the diseases, or illness”. The definition of quality of care at individual level can be simplified into two parts: whether individuals have access to the structure and process of health services, and whether such services are effective. To interpret this, technical terms like accessibility and effectiveness have been used.

Accessibility: The first half of the definition of healthcare quality emphasizes on "whether individuals have access to the structure and process of health services". The very basic dimension of health care structure is geographical/physical accessibility (e.g. living in remote rural areas and/or lack of facilities to the disabled or elderly etc.). Affordability of services is also an important aspect of accessibility as expensive care services and difficulty in seeing a doctor are barriers to access.

Organizational access is one of the "soft" components of accessibility outside the physical factors that impede or facilitate access e.g. distance, availability of transport or infrastructural elements like the presence of ramps for the disabled to enter a building. Organizational access consists of regulations, institutional and human factors. For instance, the opening time of clinical consultations, the waiting time for beds in hospitals, attitudes of the care provider, the use of a mutually understandable language for communication between doctors and patients. Interpretation of availability is done in terms of the degree of individual satisfaction to the facilities (structure) and services (process) provided by the health care system, such as availability of women doctors, experts, or the access to multi-disciplinary consultations.

Effectiveness: The second part of health services quality effectiveness, is the outcome of services provided to meet the needs and the degree of closeness to the anticipated outcome when an individual accesses such services. Effectiveness is determined by two factors: clinical care and inter-personal care.

The effectiveness of clinical care depends on whether one obtains knowledge-based care and the effectiveness of inter-personal care depends on whether interactions between doctors and patients could lead to individualized services. Effective inter-personal services need comprehensive information about the patients for co-coordinating health professionals and other resources. Patients need to share the service responsibility via discussions to access patient-centered service which in turn may reduce over-dependence on medical technology. Health policies like policy of co-ordination and integration of hospital service and community service have an impact not only on the effectiveness of clinical care but also on inter-personal care.

The quality of inter-personal services as well as clinical services is a key process of effectiveness of health services, and it is incorrect to emphasize any one aspect. The methods to measure these

two types of quality are quite different. The method used to measure customer-centered service and communications between doctors and patients is more time-consuming and expensive than searching clinical databases via computers (Yang, 2007).

1.7.2 The definition of quality health care at a population level:

Population healthcare might be a contradiction to individual healthcare. From a government point of view, the outcomes of population health are most important. The definition of quality of individual healthcare cannot be mapped directly on to the quality of population healthcare, as social background factors affecting the quality of service have to be taken into consideration. While assessing quality of care at a population level, there are three other factors that are pointed out: equity, efficiency, and cost. The quality of health care at a population level can be defined as the 'ability to obtain affordable service on the basis of efficiency and equity'.

"Equity" is a relevant factor when thinking of accessibility healthcare processes and outcomes, at the population level. It is the degree to which all individuals within a population can obtain necessary services promptly, in accordance to their needs.

Efficiency is the ratio of returns to the cost, i.e., to maximize outcomes at the lowest possible cost. Efficiency could be divided into allocation efficiency (focuses on the measures to maximize returns) and technical efficiency (focuses on technical capacities to achieve desired outcomes). As for individuals, technical efficiency is more important, which allows individual users to maximize their expected outcomes. However, such maximization is neither continuous nor affordable for population health services. Therefore, allocation efficiency should be emphasized for population health, effectively distributing resources to the areas where health could possibly be obtained at low cost. Resource allocation is determined by a society's choice, which could be justified by need and equity, at the same time resource allocation is also an interactive process and outcome.

The balance between equity and efficiency is a permanent theme for health care quality, but this does not mean that efficiency and equity are mutually exclusive. The key problem here is how to integrate economic and clinical motives with social motives.

Thus according to Yang Hui **t**he quality of individual health care is "the ability to obtain effective health services according to needs and aiming at maximizing the health benefits"; the quality of population health care is "the capacity to obtain effective services through efficient and equal means to optimize population health benefits". The core of individual health services quality is accessibility and effectiveness, while the population health service quality needs to cover every individual in the society and needs to keep balance with social health output.

Donabedian also distinguished between different levels when assessing healthcare quality (Donabedian, 1988). He outlines four levels at which quality can be assessed – individual practitioners, the care setting, the care received (and implemented) by the patient, and the care received by the community. Ovretveit's conceptualization of different levels in quality is based on sites of interventions: the health system level, the organizational level and the clinical level or macro, meso and micro level respectively (Øvretveit, 2001).

The definition of quality changes depending on the level at which it is assessed. The first is the level of healthcare services and it includes preventive, acute, chronic and palliative care (Arah et al., 2006). At this level, 'quality of care is the degree to which healthcare services for individuals and populations are effective, safe and people-centered' (WHO, 2018). The second level is the broader level of the healthcare system as a whole. Healthcare systems are of better quality when they achieve the overall goals of improved health, responsiveness, financial protection and efficiency (Busse et al., 2019). Such a broad definition of healthcare quality has its advantages as well as limitations. It can be problematic especially in the context of quality improvement. Strategies for improving access and efficiency in health systems for quality improvement initiatives may distract attention away from those strategies that contribute to increasing effectiveness, safety and patient-centeredness of care. The distinction between of health service quality and quality of health service system has been discussed in the next chapter as it is made in different quality assessment and improvement frameworks.

Conclusion

The previous review and discussions raise the question, why does quality in health services need to have the attributes of products spelt out when other industries get by with simply meeting customer requirements. It is because health services both in their production and consumption

are far more complex than other kinds of industries. The standard industrial quality management approaches are inadequate to deal with this complexity. Each individual patient-health service interaction episode consists of an intangible, ephemeral, unique, highly variable and contentious process that cannot be compared with the market. Unlike many products and services, health care has intrinsic moral and ethical dimensions which are essential considerations in any measurement of its quality. To understand this complexity and to improve quality, (Walsh, 2018) adopts a classification system that categorizes quality management into: strategic, normative and critical quality.

The preceding review of quality in healthcare reveals that there are descriptive and prescriptive definitions of quality. Descriptive definitions are usually a statement giving meaning of the term by referring to some state or phenomenon. Prescriptive definition is a convention concerning the use of a term in a certain situation or at a certain time. It uses the terms like 'ought to' or 'should be' (Harteloh & Verheggen, 1994). These definitions usually refer to different sets of actors and activities. Researchers and scientists commonly use descriptive definitions whereas managers and quality assurance professionals prefer prescriptive definitions of quality. First set of definitions is concerned with conceptual issues while the second is concerned with practical problems. It is difficult to bring into practice and implement descriptive definitions in a real-life setting.

It was pointed out that *these two kinds of definitions are a frame of reference for different activities. Scientists usually strive towards a descriptive and managers towards a prescriptive definition of quality of care. This leads to conceptual and practical problems, because a prescriptive definition cannot be deduced from a descriptive definition ('one cannot deduce an ought from an is'). So, a scientific quality assurance seems to be a contradiction-in-terminis. But as medicine is a scientific discipline from early on the wish for a scientifically based quality assurance is present* (Harteloh & Verheggen, 1994 p-262).

Donabedian's definition of quality is a descriptive one, referring to it as a property of the structure, process or outcome of care. Quality assurance mechanisms usually focus on problems in clinical practice that were attributed of low quality of care. Quality assurance for improving quality then involves that more and more aspects of care are measured and compared with

standards and criteria of quality care. This then requires formulating standards and guidelines for different aspects of care. However, the relation between measures of various aspects of care and quality as perceived by the users of services, was often not clear.

Regular inspection to evaluate conformance to prescribed standards and guidelines is an important feature of commonly used quality assurance and accreditation frameworks. Once different aspects of health care are measured and compared to prescribed standards and guidelines, how must those who fail to meet these standards and guidelines be dealt with? What are the impacts of these inspections on the quality of services delivered? It is widely recognized that the performance assessment and the report cards strategy along with public reporting of the assessment results has raised suspicion between physicians and patients. Therefore, understanding the quality measurement mechanisms and their objectives is important.

1.8 Conceptualization of research problem of 1) exploring discourses on quality in health care and 2) studying community perceptions of quality in healthcare:

1.8.1 First Part: Mapping the institutional discourse on the quality of health care:

Some frameworks of quality have explicitly focused on including healthcare quality at the service level and are concerned with the core dimension of quality like safety, effectiveness, and patient-centeredness. Whereas other elements such as accessibility, efficiency, and population health are considered part of health system performance and have also been included by some frameworks on quality. There is overall agreement on some dimensions like effectiveness, safety, and patient-centeredness of care. However, there is a divergence of opinions on access and efficiency as dimensions of quality. While it is recognized that it is important to address access and efficiency in health systems, it has been argued that it might lead to confusion about the focus of quality improvement initiatives and may distract attention away from those strategies that truly contribute to increasing effectiveness, safety, and patient-centeredness of care.

Management and marketing strategy increasingly stressed that the critical factor for business performance is customers' satisfaction as it leads to customer loyalty, repurchase intention, and even recommendation to others by word of mouth (E. W. Anderson & Sullivan, 1993; Armstrong & Kotler, 2007; Brady & Cronin Jr, 2001). With this firms needed an understanding

of the experience of customers and their perception of the service used to provide better services. This was essential for satisfying existing customers and attracting new customers. With customer perception becoming important in the industrial and service sector, the health sector also increasingly started to use patient satisfaction in their attempts to improve the quality of health services. Pursuraman's SERVQUAL model from the marketing and retail sector has been adapted and used in the health sector. In the health sector, Judith Bruce's framework on assessing quality from the client's perspective is also used for assessing quality.

Literature on the quality of health care shows that quality has been defined and assessed by experts, accreditation organizations (in the form of external evaluation), and by medical professionals themselves. With growing recognition that the acceptability of services is of crucial importance service users' perspective was also being considered while assessing quality. The here patient-related outcome was added to the earlier expert-rated outcome.

The emphasis on these structures, processes, expert-rated outcomes, and patient-rated outcomes varied depending upon who judges the quality and their motives and approaches. (saving cost, increasing profit, improving health status, following professional standards, etc.

External evaluation through accreditation organizations is another important trend in the quality assessment and improvement initiative. Performance and report cards, public reporting, and performance and report cards are a recent trend in quality assessment and improvement initiatives. There are many developments happening in the discourse of quality of health care that have an impact on the health system development and in turn on the health of the population.

A study of the discourse of quality is done to have an idea about all initiatives and strategies of quality improvement for their strengths and weaknesses, their scope and limitations along with their value and implications.

1.8.2 Second Part: Studying community perception of the quality of health services

A review of the literature on the quality of health care has shown that many quality improvement initiatives were focusing on processes and expert-rated outcome data. Quality was measured/ assessed and judged by experts (professionals, regulatory bodies, or accreditation organizations).

After recognizing the importance of the user's perspective in quality assessment, attempts were made to involve the patient's concern in quality assessment. Literature shows that initiatives of involving the user's perspective in the quality assessment were limited to the exercise of measuring patient satisfaction. Now patient satisfaction with services is being used in the assessment of the quality of health care by many agencies and accreditation organizations.

Different studies have shown serious limitations of using patients' satisfaction for quality assessment at a conceptual and implementation level. Studying patient satisfaction for assessment of the quality of health care will address the concerns of only those who have managed to negotiate with the health system to become patients. If this is used for assessing and judging the quality of health care services and in turn for policy and planning for health services, which are meant for the whole population, then there are chances of missing the concerns and voices of non-users or those who have failed to become patients despite being unhealthy. The health service system is a social institution; hence, concerns of the community become very important in determining the nature of the health service system, the kind of health care given, and in turn in defining the quality of health care. This study was planned to explore perceptions of the rural community about the quality of health care.

Placed squarely in the realm of human interaction, the way providers perceive the care needed and the care they provide, and the way clients perceive the care they need and are given, depends on complex, social, and culturally constructed needs and expectations, raising the question who defines quality and rendering quality a relative concept that is influenced by more complex social determinants. These determinants include gender, race, caste, socio-economic status, ethnicity, religion, region, etc. There is a large body of literature showing differences in the quality of services provided based on gender, race, ethnicity, religion, and socio-economic status.

In India, caste is an important determinant, along with gender, race, ethnicity, socio-economic status as suggested above, factors shaping the health of the population, their access to health services with expectations, and experience with available health services. This study attempts to examine community perceptions of quality among the two caste groups viz. 'Mang' (Dalit) and Maratha (upper caste).

1.9 Objectives of Study:

1. Studying the discourse of quality of care in the available literature to identify various perspectives on the quality of health care services from different scholars and agencies.

2. To explore community perceptions of quality in healthcare especially of the Mang and Maratha communities in the Nanded district

3. To study the implications of these perceptions for public health and how they can be integrated into public health policy and planning or quality improvement initiatives

1.10 Research questions:

- What are the different approaches to assessing the quality of care in the contemporary situation as in use or proposed by scholars, accreditation bodies, and other agencies?

- What are perceptions of the quality of health care among the 'Mang' (Dalit) community and Maratha (upper caste) in the present context?

- In what way can the various perspectives and perceptions be used to develop the principles for defining the quality of health services and policy setting for improving quality?

1.11 Methodology:

1.11.1 First Part: Mapping the institutional discourse on the quality of health care:

Further review of the literature is being done to see how different scholars, accreditation organizations, institutes, and organizations working on standardization of care and health systems development have defined the quality of health care. An attempt is made to analyze whether these different definitions, approaches, and understanding of the quality of health care address the concerns and issues involved in the broader principles of public health viz. universality, equity, and comprehensiveness, and are in tune with principles of social justice, human rights and the right to health and health care

Different criteria can be used to assess the quality of healthcare services, which include criteria related to structures, institutional processes, clinical processes, and outcomes. The concept of accessibility and patient and community satisfaction are also crucial while understanding the quality of health care. Efforts is being made to study the pros and cons of using these criteria in isolation or leaving behind any of the criteria while assessing the quality of health care.

Different attempts at improving health service systems have been studied and an analysis of the focus of these attempts has been done by studying what aspects of quality were being addressed through these attempts. In these attempts literature and studies done in different countries and areas on issues like efficiency, cost-effectiveness, cost-cutting, health systems performance, responsiveness, patient safety, impact assessment studies, fairness and equity, health inequality, medical and health care ethics, studies done on the doctor-patient relationship, studies done on patient satisfaction and on patient-centeredness of services, quality assurance and TQM studies in the health care sector, etc have been reviewed.

Efforts are being made to show how the quality of health care if viewed from a public health perspective is a broader concept involving all input, process, and outcome-related factors along with issues like safety, accessibility, fairness, responsiveness, affordability, and efficiency as against its pre-dominant understanding revolving around excellence and focused on the transactional level of health services to the patient.

1.11.2 Methods used:

A review of the literature was done through secondary sources from books, journals report other material produced by different agencies working on quality regulation and accreditation organizations. The literature search was done by using different portals like pub-med, Medline, Jstor, science direct, google scholar, etc. Cross references were searched through different web-based search engines and library resources available in Delhi.

Accessible literature then was screened for relevance to the theme of understanding the concept of quality, its dimension, and different frameworks/ models of quality in the health sector. Research material available for patient-rated quality assessment and patient satisfaction study

was also done. Studies on social determinants of the quality of health services were also examined to further understand on concept and framework of quality in healthcare.

1.11.3 Second Part: Studying community perception of quality of health services.

A review article (Meta-analysis) on theoretical and methodological issues of health perception studies by Ritu Priya and Mita Deshpande (2007) shows that health behaviour and perception studies have supported both techno-centric and socially oriented streams of public health. They showed that there was greater comprehensiveness in defining the subject matter as well as in the analytical frame they use for determinants by studies of the later stream. The others were limited in scope and isolated the problems to be studied.

They have analyzed these studies based on certain relevant features. The features identified include:

1. Primary focus on 'behaviour' or 'perceptions': Though more complex than health-related 'behaviour 'it is important to study health-related 'perceptions' because they are likely to be a truer reflection of what people 'feel' and 'want'. Behaviour is influenced by existing constraints and services available.

2. Studying perceptions devoid of specificities of social stratification or locating perceptions within an understanding of social stratification.

3. Focus on Disease or on Health and Well Being / Quality of Life-

4. The Biomedical framework as the only legitimate perspective or Recognition of other forms of knowledge as legitimate'

5. A Rigid pre-determined framework or a flexible conceptualization and design which allows the perceptual framework of the study group to shape the research

6. The Etic vs. The Emic Perspective and Objective Vs. Subjective Data: The former attempts to understand health behaviour and indigenous systems within the worldview and value systems of the group whereas the latter attempt it within the framework of modern medicine.

7. An Ahistorical or a Historical approach to health perceptions
8. Level of Organization Studied - Individual vs. Collectivity
9. Qualitative or Quantitative Data

They have categorized health perception studies along the disciplinary continuum as;

Psychological studies, applied psychological studies, sociological/ social anthropology/culture logic studies, traditional anthropology and ethnography, rapid assessment procedures (RAPs), explanatory models, illness narratives, social anthropology, integrated approaches, and integrating social anthropology with epidemiology.

Sociological/Social Anthropology/ Culturological Studies:

The more context-sensitive studies relate perceptions to socio-economic, political, cultural, environmental, infrastructural, and institutional conditions. The sociological study focuses on the influence of social structure and institutions on peoples' behaviour and perceptions. The culturological approach focuses on studying the underlying meaning given to the social structure, institutions, problems, and optional health behaviours by cultural cognitive structures.

A further classification has been made between studies that use normative and interpretive approaches. Normative studies explain the role that social structures and institutions play in the constitution of the subjectivity of individuals and subgroups within society. These studies explain the existence of a direct link between society and subjective experience of health and illness. Interpretative approaches emphasize the actor's capacity both to attach a meaning to different social situations and to act and not only 'react' accordingly.

The proposed study will use a social anthropological and normative approach combined with an epidemiological perspective. Keeping the context of change in health services and health status and morbidity pattern as the background, it will examine the perceptions of the quality of the health services among two communities representing the top and bottom of the social hierarchy in the rural population. It will endeavor to elicit and describe their use of the health service system to manage their problem and perception of quality of health care by placing them within the world view and value system (i.e. emic perspective) of the study groups.

1.11.4 Methods used:

In-depth interviews of the selected families and the individuals on their care-seeking journey. The interviewees will enquire about their experience with health services and their reflections on expectations and actual experiences of health services used.

Group discussions with study groups on changes in health services over time perceptions of quality of care through their reflections on and undesirable experiences of seeking care.

1.12 Area of Study:

Nanded district has been selected for this study; it is an averagely performing district of Marathwada province of Maharashtra in terms of HDI rankings, education and health status wise, demography, urbanization, and industrialization. This particular district of Marathwada was selected for this study as it has a medical college and teaching hospital that serves as a tertiary or apex level of care. The researcher also has past experience working in this area and has familiarity with the area and community.

The area for study, within the district, is selected by following district health service system structure linkages i.e. by selecting CHC and PHC. Averagely performing CHC and PHC, as told by DHO and other health officials and based on data on health status and data on the availability of infrastructure, manpower, medicines, and equipment, were selected. While selecting CHC, distance from District Hospital was also considered. The link CHC Kandhar selected for the study is averagely performing which is neither too close nor too far from the district hospital. In Maharashtra, the level of CHC is occupied by two types of institutions, Sub District Hospitals (SDH) and Rural Hospitals (RH). SDH is upgraded RH with more infrastructure and human resources. Only two SDH were functioning in the district therefore an RH was selected for this study. A similar logic is followed while selecting link PHC about the selected CHC/ RH. However, it was found that all the PHCs in this block were on average 20 km from block town RH except Panshevadi PHC. There was a possibility population under all these distant PHCs might be using referral services from adjacent block towns if it what convenient and shorter distances. Therefore, to maintain some link to the prescribed referral channels Panshevadi PHC

was selected as it was the closest PHC to CHC/RH Kandhar. The population under this PHC was using services from the block town of Kandhar for their routine health care needs.

1.13 Selection of village

There were two options for selecting a village for this study under Panshevadi PHC. The first option was to select a sub-center village. And another option was to select a village under sub-center i.e. a village without any health infrastructure. With the given health service system and its network majority of villages in our country, including the state of Maharashtra and Nanded district don't have any government healthcare institution. The number of villages having a sub-center varies in different states and districts- this number is less that those without any government health institution. The number of villages having PHC is smaller than those of having sub-centres.

Ideally, a village having no health institution would have been a better choice as it represents the condition of a large number of villages. The second choice could have been that of a sub-center village. However, given the centrality of the use of services offered by a doctor in care-seeking journeys of people these two types of villages, with the absence of a doctor, would have given a bleak picture of experiences with health services and very high levels of expectations. Given the enormity of issues anticipated in that study the easier option, is PHC village opted? This level of PHC village with the presence of a doctor in PHC gave additional information on experiences and expectations from health services offered at the level PHC and its doctor. With these considerations, the PHC village of Panshevadi was selected for studying the community perception of quality in healthcare.

1.14 Study Population and sampling

Panshevadi had a total population of around 1900. There were 325 households in the village. Panshevadi village is a multi-caste village. The village had around 200 households from the Maratha community, 50 households from the Mahar/ Neo-Buddhist community, 40 households from the Mang community, and the rest of the households from other communities. Maratha community is the dominant, majority, and most endowed community in the village. Mang community is an untouchable Dalit community occupying the lowest status in the social and

power hierarchy in the village. These two communities were selected for studying perceptions of quality. All the families of these two communities formed the study universe. For selecting respondents for the study all the families visited both communities over three half month's stay in the village. All those families who had someone with a history of illness and seeking care, especially in the last three years were requested for an interview. Those who agreed to an interview and were available for the interview have been selected and interviewed to study their perception of quality in health care. The length and breadth of localities of both communities in the village were covered. Most of the families were welcoming and receptive and agreed for giving an interview for the study. Depending on mutual convenience, the day and timing were fixed and interviews were conducted.

However, in the case of a few families despite their consent interview could not be conducted as two families gave the same time and only one interview could be conducted. Some such interviews were postponed and were done on later occasions by fixing another time slot. However, in the case of some families, such revisit and interview did not materialize as the timing did not match. Most of the respondents preferred morning 9 am or evening 7-8 timing as at this time most of the family members- those who are articulate or head of the family member- were available and relatively free for interaction. Occasionally interviews were done in the afternoon between 2-4 pm as well. The timing of interviews is given to convey that due to these preferred time slots some interviews had to be postponed and later did materialize despite the mutual agreement.

Fieldwork was done from March till mid-June, 2010. This peak summer season, hot and sunny days made these interviews difficult during the peak heat of the day. In addition to this heat, another problem that was encountered was the out-migration in search of work and wages in this season from the Mang community. Therefore, some families did not have members who had the confidence of agreeing and giving an interview in detail. Some houses were locked. Most of the available families of the Mang community were also visited on multiple occasions to take their interviews.

A total of 45 interviews were done along with 3 group discussions. Some of these interviews were short and not satisfactory. However, most of the interviews were satisfactory with a

forthcoming and interested family member discussing the care-seeking journey and their reflections on it. Though the interview was initiated and was anchored by one person, who had sought care in the last three years, in due course of the interview other family members, neighbors, and friends who participated in the interview gave their experiences and reflections as well. An attempt was made to encourage them to talk so that a broader understanding of how the community thinks of quality in health care could be ascertained. The interview ranged from 30 minutes to two hours, with most of the interviews being of one to one and half hour duration.

Three group discussions were simultaneous group discussions with a group of already sitting members of the community at common places in the village viz. near a flag post in the village, near a temple in the village, and another near the bus stand of the village. The group consisted of males only, with an age range of 20 years to 70 years, and had a number of around 6-10 members. Members participated in the discussion for various duration of time depending on their convenience as the conversation kept going. The group discussions were very reflective involving some questioning among each other and revisiting the viewpoints expressed.

1.15 Profile of Nanded District:

Nanded lies in the Godavari river basin and forms the easternmost district of Maharashtra. It is situated between 18 16'and 19 55' north latitude, 76 55 and 78 19' east longitude. It is surrounded by Yawatmal district in the north, Andhra Pradesh state in the east, Karnataka state to the south, Latur district to the southwest, and Parabhani district in the west.

Nanded, located in the eastern part of Marathwada province, covers an area of 10528 sq km. i.e. 3.42% of the total area of the district and population of 2868158 i.e. 2.96% of the total population of the state which is 96752247. The district is administratively divided into 16 tehsils. The total number of villages in the district is 1572 with 1313 gram panchayats.

Nanded is primarily a district of Marathi-speaking people. Some people from Biloli and Deglur tehsils speak the Telugu language also.

Administration: For administrative purposes, the district is divided into 16 tehsils. The district collector along with the district judge, superintendent of police, chief executive officer of the

Zilla Parishads, and other senior officers of state government looks after the administration, developmental and regulatory functions of the district.

At the tehsil level, the Tehsildar along with the block development officer of the Panchayat Samiti, the judicial magistrate, and other officers look after their respective departments for developmental and regulatory functions.

Demography: 24.02% of the total population lives in an urban area, ranking 18th in terms of the urban population in the state. Nanded ranks 15th in the state for population density with population density being 272 (Nanded), as against the state average of 314 (Maharashtra) in 2001. 16.01% of the population is of the age group of 0-6 years.

Human Development: Human development index wise Nanded with an HDI of 0.37 occupies 29th rank among 35 districts of Maharashtra. The human development index of Maharashtra is 0.58. The per capita district domestic product of the Nanded district is 8,788 Rs. whereas per capita domestic product of Maharashtra is 15,804 Rs. Nanded ranks 32nd in terms of Per Capita District Domestic Product. 29.3% of families in the Nanded district are below the poverty line as compared to 34.55% of families in Maharashtra.

Health status: Infant Mortality Rate (IMR) of the Nanded district is 68/1000 with male IMR being 66 and female IMR being 76/1000. The Child Mortality Rate of the Nanded district is 87/1000 as against 91/1000 of Maharashtra.

1.16 The link CHC: Kandhar

In the Nanded district, there are a total of 14 rural hospitals/ CHCs coming under the administrative control of the civil surgeon. Rural hospitals/ CHCs provide mainly curative services and act as referral centres for all PHCs in that Taluka. Rural hospitals/ CHCs are usually located at the Taluka Head Quarters and serve the area coming under that particular Taluka. The study area is being served by the rural hospital/ CHC Kandhar as a referral center. Kandhar is located 52 km away from Nanded, in the basin of the river Manar. This town is 13 km away from the Nanded-Latur state highway.

The Rural hospital/ CHC in Kandhar is situated at the heart of the town on the main road passing through the town. The rural hospital is a 30 bedded hospital, having an infrastructure of 23 rooms. The Health assistant and MPWs use an old building of RH for implementing the National Health Programs.

The THO is a corollary to the DHO but at the taluka level, the important difference is that the THO is located separately within the rural hospital campus with no administrative control of the Panchayat Samiti, whereas the DHO office is located in the ZP campus and comes under the jurisdiction of the ZP. The THO oversees the activities of five PHCs, namely Barul, Pethawadaj, Kurula, Panshevadi, Usman Nagar, and 32 sub-centres of the Kandhar taluka. The THO is given the responsibility of supervising the work of national health programs in the whole taluka and the functioning of all the five PHCs and their sub-centres in the taluka.

1.17 Profile of Panshevadi village

The link PHC selected for this study is located in Kandhar Taluka, 16 km away from Kandhar town. It is connected by a tarred road to Kandhar and Ahmeadpur. The whole area is catered to by a PHC situated in the Balaghat mountain ranges and characterized by stony and thin soil. The area is dry having only one season crop (monsoon season Kharif crop) except in a few areas, which are irrigated with the groundwater, that grows two seasons of the crop. Most of the agricultural land around the village is used for rain-fed agriculture. There on small check dam build on a water stream near the village which ensures the availability of drinking water for the village around the year. The availability of sufficient drinking water is an important problem in many of the surrounding villages, especially during summer. The check dam is also helpful for agriculture, especially for the land surrounding the dam.

The village has a PHC running in the erstwhile sub-center and a panchayat building adjacent to it. There is no PHC building of its own. There are two schools in the village. The village is connected by a street and has a state public transport bus, which comes twice a day from the block town of Kandhar. Apart from the bus, the transportation that is commonly used to travel to Kandhar is by multiple auto rickshaws providing their services.

1.18 Profile of Maratha Community:

Identification: Marathas are a Marathi-speaking people found on the Deccan Plateau throughout the present state of Maharashtra and nearby areas. The word "Kunbi" derives from the Sanskrit "Kutumbin" or "householder" (i.e., a settled person with a home and land). Marathas/Kunbis are the dominant castes in Maharashtra State. They are landowners and cultivators, and they make up about 50 percent of the population. The distinction between Marathas and Kunbis is confused, and the former consider themselves superior to the latter. The Marathas were traditionally chieftains and Warriors who claimed Kshatriya descent. The Kunbis are primarily cultivators. The distinction between them seems mostly one of wealth, and we may assume a common origin for both (http://www.everyculture.com/South-Asia/Maratha.html).

Marathas claim to be Kshatriyas descended from the four ancient royal vanshas, or branches. In support, they point out that many of their kula, or family names, are common clan names amongst the Rajputs, who are undoubtedly Kshatriyas. In the past royal Maratha houses have intermarried with the Rajputs (http://www.everyculture.com/South-Asia/Maratha.html).

The Maratha cultivators, known as Kunbis, and other service castes, such as Malis (gardeners), Telis (oil pressers), and Sutars (carpenters) do not consider themselves Kshatriyas. Nevertheless, the fact that the Kunbis and Marathas belong to one social group is emphasized by the common occurrence of Maratha-Kunbi marriages.

Economy: In general, the majority of Marathas are cultivators. They were mainly grant holders, landowners, soldiers, and cultivators. A few were ruling chiefs. For the most part, the patils (village headmen) in the central Deccan belong to this caste. Some are traders, and many are in the army or other branches of government service.

In the plateau region, the fields are ploughed with the help of bullocks. Almost every farmer except the poorest has cattle and takes great pride in them. The greatest agricultural festival is Bendur or Pola, when the cattle are decorated and taken in procession.

Staple foods are wheat cakes, rice, lentils, clarified butter, vegetables, and condiments. Less affluent people usually eat jowar (sorghum), bajari (spiked millet), and lentils, while the poorest will subsist on millets seasoned with spices. All Marathas eat flesh and fish, though not beef or

pork. Marathas seldom drink liquor, though no caste rule forbids liquor or narcotics. Beedi smoking is Common among men.

Kinship, Marriage, and Family: Marathas practice kul or devak exogamy. Devaks are totemic groups that worship a common devak symbol. Kul is defined as a "family," and it is a lineage made up of extended families. Devak is an alternative name for this. Although they claim to have gotras, gotra exogamy is not essential. These are clan categories adopted from north India, but most of the Marathas do not know to which gotra they belong. Similarly, north Indian village exogamy is not practiced by Marathas. Cross-cousin marriage is allowed; so is marriage with a deceased wife's sister. Two brothers may marry two sisters. Polygyny is allowed and practiced, but polyandry is unknown (http://www.everyculture.com/South-Asia/Maratha.html). Boys are generally married between the ages of 18 and 25, and girls are traditionally in a slightly lower age group. Widow re-marriage and divorce are strictly prohibited.

The property was held and transmitted from male to male. When no male heir existed, the adoption of one was the usual rule: a daughter's son could be adopted. The property was owned jointly by all male family members in certain proportions. Widows and unmarried daughters had rights to maintenance

Political Organization and Social Control: In the cities and small towns some Marathas have risen to very high positions in government service, which has given them political power. Positions of importance in the cooperative sugar mills, in the managing committees of schools, in the municipalities, and in the panchayat samitis are held by Marathas in most cases. As the Marathas are the majority agricultural Community with smallholdings in this region, they still belong to the middle and lower-income groups as a whole; but there has arisen among them a status of the educated elite who are in higher administrative services and industry and who hold political power. This power to a great extent has its basis in the votes of the small rural landholder.

1.19 Profile of Mang community:

Mang/ Matang is said to have originated from Jambu Rishi sometimes called Matang Rishi. Matang Rishi was a bold warrior of great valor. There were small kingdoms of Matang in south

India and the Chandel kingdom is said to have been one of them. They have been described in Sanskrit literature by the name Matang and it is said that their popular name Mang is derived from a Sanskrit word. However, the word Mang means to beg, and seeking alms was one of their vocations. Russel and Hiralal (Russel & Hiralal, 1916) have written that 'during an eclipse, the Mangs beg because the demons Rahu and Ketu who is believed to swallow the sun and moon on such occasion, are both Mangs, and devout Hindus give alms to their fellow caste men to appease them'.

The Mangs are divided into four subgroups, namely Mang Garodi, Mang Garudi, Dhakani Mang, and Somvanshi Mang. These subgroups are further divided into exogamous clans such as Admane, Kathale, jogdand, Lokhande, Kuchkar, Bhise, Diwate, and more Jadhav, etc. they name as surnames. A large number of the sixteen exogamous surnames, as reported by Hassan (Siraj-ul-Hassan, 1920) are in existence.

As per the 1971 census of India, there are five subgroups of Mang. They are Mang, Radhe Mang, Mang Garodi, Mang Garudi, and Mang Matang. The Mangs of Maharashtra are known as Matang. They are spread all over the state but their larger concentration is in Osmanabad, Sholapur, Pune, Ahmednagar, Aurangabad, Parbhani, Jalana, and Nanded districts. They are predominantly found in rural areas (Singh, 2004).

Their social organization is characterized by patrilineal descent and inheritance, and patrilocal residence. Monogamous marriage is the norm though occasionally a man may have more than one wife. Marriages are usually settled through negotiations. Marriages are settled by elders and community men. Earlier there was a bride price to be given to the girl's father. Now dowry is given to the boy's father as per the capacity of the girl's father. Dowry is given in cash or kind and the custom of paying the bride price is on the wane. Residence after marriage is patrilocal. Divorce and remarriage are socially approved of. Divorce is permissible to both husband and wife. Remarriage is permitted for divorcees and widows and widowers. Marriage symbols for women are mangalsutra/ kalipot and toe rings (jodave). Property is inherited equally by the sons. The elder son succeeds the father.

The settlements of Mangs, who live on the outskirts of the village, are called Mangwadas. Most of them have their own houses which are generally; in the village, kaccha houses, or are in dilapidated condition. Most of the houses in urban areas are in slums and on claimed land.

Their mother tongue is marathi which is used for inter-group communication as well. Devnagari is the script used by them. They are non-vegetarian and take beef and pork.

They profess the Hindu religion and Mahadev or Shiva is regarded as a community deity. Some families from this caste have a tradition of giving/ donating their son to the goddess Mariai as potraj. Along with this, traditions like donating sons as waghya and daughters as murali (dancers in tamasha and religious festivals) and devadasi have been their caste traditions. These customs and traditions are still followed, predominantly in Kolhapur and Sangali districts of Maharashtra, not necessarily voluntarily as there is explicit or implicit pressure from upper caste groups specifically for devadasi tradition and for halagi (drum) beating during ceremonies and functions. Caste hierarchies are still maintained and upper caste groups continue to hold power and inflict caste atrocities on this caste group. 76% of Mang who have faced some kind of caste atrocity have avoided registering a police complaint for the fear of backlash from Hindu upper caste groups and atrocities of police (Ramayya, Darokar S., 2007).

In historical accounts, the Mangs were treated as musicians, songsters, strangers, hangmen for criminals, watchmen, and messengers. During the reign of Shivaji Maharaj these people were engaged as messengers, spies, watchmen, and playing sirens. Their traditional occupation is skinning/ tanning, and drum beating (Singh, 2004). Besides a large number of them are agricultural laborers.

They are largely landless; only a few of them are small landowners (Ramayya, Darokar S., 2007). In their study, involving all 35 districts of Maharashtra, of 5005 houses chosen through multistage stratified sampling design show that 83% of families were landless. Of the 17% who own land, their land holding is up to 1 or 2 acres and is dry and grazing land which was allocated during land distribution.

Their main occupation is preparing ropes from hemp/ kekati and sisal bark (known as dorkhand) and brooms from date palm. They make ropes from sisal leaves. They make brooms and other

materials like nada, kasare, kanuyua, gofani, miski etc. they are also musicians and form band parties in villages and cities. They play music at a wedding, cremation, and other functions. Their traditional occupations like rope and broom-making are very much affected by developments in technology. New nylon and polyester thread, and new brooms of different kinds have been introduced. They also do the work of removing a dead animal from the village and skinning it. They are also engaged as agricultural laborers (Ramayya, Darokar S., 2007).

(Ramayya, Darokar S., 2007) in their study show that 76.6% work as a daily wage laborer and involves work related to agriculture or work like porter, rickshaw pulling, rag picking, etc. Only 8% were having salaried work either in the government or private sector. 0f these 8% people 71 % had an annual income in the range of 4500 to 35000 Rs. Only 1.6% had an annual income of 1.5 lakh and above. Some are employed in government services.

Women have a versatile role in the family, but their status is lower than the men's. Women do household work, look after children; cook food; collect fuel and potable water, work as agricultural laborers, make ropes brooms, etc. some women from this community also render the services of midwives (Singh, 2004).

1.20 Ethical considerations:

1) The researcher will ensure that any information elicited out of the interviews with the family members will be kept guarded, and assurance would be given to the respondents that information collected would be used confidentially maintaining anonymity about illness and other personal information.

2) Consent: researcher would convey to the respondents about the risks and potential benefits of participation in the study and ensure that the respondents are fully aware that they can withdraw from being a part of the study whenever they feel so.

3) Feedback of the findings on perceptions to the communities to get their feedback on it to ensure as close a representation of their viewpoints as possible will be done before publishing the finding in journals or books.

1.21 Analysis:

The in-depth interviews and group discussions were analyzed by studying the care-seeking journey of respondents and their reflections on those care-seeking journeys. Their experiences and expectations about the care-seeking journey were studied for identifying desirable and undesirable aspects of that care-seeking experience.

Analysis of those care-seeking journeys was done to understand their perceptions of quality. These emerging perceptions of quality then have been grouped based on the level at which they operate or are amenable to action.

1.22 Limitations :

As the study population is not a representative sample of the whole population so its perceptions cannot be generalized to all communities. Many more studies like this in different socio-economic groups and regions will help in laying out some principles about perceptions of the quality of health care.

1.23 Care Seeking Journey for studying community perceptions

'Quality' in health care is a very complex phenomenon with technical, objective, and subjective dimensions, making assessing perceptions of quality a challenging task. Health care providers, especially doctors, with knowledge and experience of the components of health service delivery and its technical dimensions have the advantage of formulating ideas and opinion on 'quality' in health care. There constant interaction with patients from diverse backgrounds over a long time while providing health care and some sensitivity has enabled health care providers to understand and reflect on what patients think about the quality of health services provided.

However, the reverse is not really possible; ordinary people do not have a similar advantage. Therefore, communicating questions on perceptions of the quality of health care can be more challenging. Questions could be understood differently by different people, depending on their socialization and experience of seeking health care for their own self or their near and dear ones. With limited knowledge of technical dimensions of medical care and complexities of the treatment process (with components ranging from infrastructure, technology, expert human

resources and their practices etc.), preferences and priorities of lay people seeking care tend to be shaped differently as compared to providers.

The popular assumption is that medical care involves a set of specialized knowledge, and health care practitioners would follow the rational practice by being truthful and adhering to medical, scientific knowledge. However, over the last decade, irrational and unethical medical practices, health care providers' financial motives, commissions and kickback are increasing. People in general have also started to realize and recognize these irrational practices and their trust in medical professionals in eroding increasingly. This context of health services, makes asking questions to understand perceptions of quality of health care among ordinary people challenging.

The word quality or its Marathi equivalent ‘darja’ or ‘Gunavatta’is also not used in colloquial parlance; its unfamiliarity made it challenging to communicate both the word and the notion of ‘quality’ to the respondents. People evaluated or reflected on the health care services or their experience with health care services in terms of good, average, poor, or bad but not in terms of quality. Quality was articulated through expressions like average, good, poor, bad etc. People’s evaluations or reflections on health services and their experience included various components, the most important concerns were obtaining relief from suffering or cure from the ailment and the affordability of the services.

1.23.1 Care seeking Journey:

Therefore, to understand people’s perceptions of ‘quality’ in health care, it was important to go beyond the direct question of what respondents meant by quality health services. To understand their perception of quality of health care, their reflections on their experience with health care services were used. They were asked questions about illness and care seeking experience in the recent past, preferably within three years preceding the data collection, and a discussion was conducted with them about their journey of care seeking. Issues like, what they felt about the care that they received; what their opinions on strengths and weaknesses of process of care that they received were; what they liked or disliked about the care that they were given; their expectations; and their suggestions for betterment of services that they received were discussed. An attempt was also made to discuss the care seeking journey with public and private sector health care providers and understand the relative advantages and disadvantages that these

providers offered; good, average, poor or undesirable aspects in their care seeking experience. Different levels of health care delivery were also discussed for their contribution to the different aspects of quality experienced by the people.

The starting point and major component of the interaction was centered on an individual with a history of seeking care, preferably with indoor admission (OPD + IPD) care. However, the discussion also invited the participation of curious and willing onlookers among family members or neighbors, who were attendants of patients, who wanted to convey their experience of seeking care in the on-going discussion. The objective was to understand the community's perceptions of quality so, this process helped in getting more insights from community members about their experience and added to the reflections on health care and its quality.

These reflections obtained during the discussion, through probing and follow up questions, are used to construct/understand their perceptions of quality. People's experience and expectations from the health system about the care that they received is being used to understand their perceptions of quality.

1.24 Health care providers of the care seeking journeys:

Respondents for the study were from Maratha and Mang communities of Panshevadi village. Health care institutions and providers that emerged in the interaction with community members ranged from those at the village level to the top medical colleges in capital cities of Maharashtra and Telangana- Mumbai and Hyderabad, respectively. Health care providers that were sought by people from the village comprised traditional healers, ANM, Multi-purpose Worker (MPW), the medical officer from the same village and the Primary Health Centre (PHC). A few traditional healers from other villages, block towns and even other districts had also been consulted by residents of Panshevadi village, medical officers at Community Health Centre (CHC)/ Rural Hospitals (RH) and medical officers and other staff from Kandhar, Mukhed, Loha from Nanded district and Ahamedpur RH of Latur District were also sought by some community members, so have contributed to their experience of quality of health care. General practitioners from the private sector in these block towns from diverse systems of medicine with qualifications ranging from MBBS, BAMS, BHMS, and practitioners of modern medicine who appeared to have no qualification in the field of medicine to local quacks equipped with seemingly dubious and

suspect course certificates were also used extensively by the public for routine illnesses. The specialist doctors from diverse specialties from government and private medical colleges in district town of Nanded, Aurangabad, Pune, Mumbai; and from private sector individual specialty or multispecialty hospitals in Nanded, Aurangabad and Hyderabad were constituents of their care-seeking experience. Similarly, medical interventions from some super specialists from these towns were also sought by people for relief from their suffering. All these varied experiences of seeking care have contributed in shaping their perceptions of quality.

The discussion with respondents was held with a checklist to cover important aspects of quality of health care.

1.25 Socio-demographic profile of respondents:

The respondents were from Panshevadi village from the Mang and Maratha communities. Some of them brought in their experience as attendants to their relatives from other villages. The interviews conducted covered patients from diverse age groups including newborns, infants, children, adults and the elderly. Respondents from both sexes were fairly represented in the respondents. The village was from a socio-economically backward region of Marathwada in Maharashtra, with most of the respondents being lower middle class, involved in agriculture. The respondents from the Maratha community were mostly farmers, however some were engaged in regular service sector jobs working as, teachers, ambulance drivers, bus conductors, clerks, police and paramilitary personnel, a retired bank manager among others. The agricultural land holding of most of the respondents was less than 10 acres with average being 4-5 acres for Maratha community respondents. Mang community respondents were mostly landless with a small minority among them in regular salaried work. Most of them worked as casual wage labor, with seasonal employment in agriculture or as migrant workers in nearby cities, depending on the time of the year. Some of the respondents were skilled workers who were self-employed E.g., carpenters. Most women were home makers and working seasonally in their family's agricultural fields or laboring for wages in others'.

The educational status of respondents ranged from being uneducated to a very few respondents having a Masters degree. However, most of them had some school education usually less than class 12, with a few having completed graduation.

1.26 Illnesses and health conditions covered:

An attempt was made to cover all types of common illnesses and care seeking experiences prevalent in the region. The interviews with respondents from the village covered care seeking experiences for common illnesses like fevers, diarrhea, GI problems, gastritis, pneumonia, malaria, common injuries, aches and pains and joint pains including common chronic ailments like diabetes, hypertension etc. Less frequent but important health problems like hemiplegia, post traumatic paraplegia, epilepsy, spondylitis, muscular degeneration, asthma, psoriasis, dengue, chikungunya etc. were also covered in the study of care seeking journeys. Surgical interventions for minor surgeries like abscess drainage, surgical removal of small swellings etc. and major surgeries like cataract, gall bladder removal, surgeries for fractures, hysterectomies etc. also formed a part of care seeking experiences. Commonly encountered health emergencies like trauma, injuries, and snake bites were also covered. Health seeking experiences for routine out-patient, and in-patient care from both private and public sector health institutions were covered including the experience of care seeking in emergency health conditions. Routine health events like pregnancy, child birth and post-natal care experiences were also brought in to have a comprehensive idea about their perceptions of quality in healthcare. Caution was taken to cover the experience of care seeking for common illnesses of children and women. Respondents also spoke of experiences with services provided under national health programs like RCH (immunization, FP, ANC, PNC, JSY, Malaria). Experiences from patients of TB, Leprosy were planned but could not be covered because it was not possible meet them.

1.27 Perception quality from their Care seeking journey

Discussions on care seeking journeys with the community members of Panshevadi village revealed a range of issues relevant for understanding their perceptions of quality.

It was observed in discussions on health care seeking, that some of the perceptions of quality of health care were based on both the experience of the self as well as of other people. Overall image of the health care institution and providers also shaped many decisions on health care and how its quality was perceived.

The experiences of self and others, overall image of the provider/hospital and perception of its quality affected the choice of health provider and experience of quality in significant ways.

Hence, examining the choice of health care providers offers the possibility of understanding people's perceptions of quality. Sometimes this choice of health care provider or institutions is not always an informed and pleasant decision. Often, circumstances are such that they are forced, knowingly or unknowingly, sometimes unwillingly, to decide on using a provider or institution.

Post-choice, the actual experience could both have coincided and/or differed from their expectation and overall image of the service, provider and institution. Apart from the anticipatory or reputation or brand image-based factors, the actual experiential aspect of the care seeking journey was investigated and used to construct their perceptions of quality. This experiential component informed their perceptions of quality significantly. Explorations of the experience of seeking care to construct their perceptions of quality were anchored in the experience of the respondent, but as mentioned earlier, have also included experiences of family members and attendants who were part of the care seeking journey and also willingly participated in these exploratory discussions.

When analyzed carefully, this experiential domain of seeking care revealed factors operating at multiple levels and having a bearing on quality of health care. These factors have been used for constructing their perceptions of quality in health care. The first level at which these factors operate is that of institutional mechanisms and processes which are generally beyond the control of the existing team of health care providers or the users of health services.

The second group of factors operate at the interface between healthcare providers/institutions and users of services. These factors contribute in a major way to people's experiences of seeking care and in-turn inform and construct perceptions of quality in health care. The factors have further been divided into those related to clinical/medical care, nursing and para-clinical care, and support services and have been further discussed with important themes that emerged and have relevance for understanding perceptions of quality in health care.

The cost incurred for medical care was a very important factor that was articulated in most of the community members' care-seeking experiences. Therefore, cost of care has been discussed in a separate section as factor shaping perceptions of quality.

The inquiry with community members brought out some interesting sociological dimensions in the care seeking experience, so they too have been used to construct perceptions of quality.

Suggestions for betterment or improvement of health services as suggested by the respondent revealed their preferences and have been used to construct their perceptions of quality.

All these factors have been discussed in detail in subsequent chapters.

1.28 Analytical approach

Data for studying community perceptions of quality in Panshevadi was collected through three and half months stay in the village. A total of 40 in-depth interviews were carried out among Mang and Maratha communities (two major communities of the village constituting 70 percent of the population). The in-depth interviews explored the respondents' care seeking journeys for their illnesses preferably within the three years preceding the time of data collection. Information was sought through probing what they felt, preferred, expected, liked, and disliked at every stage of their care seeking journey. Respondents were also asked about their reasons for choosing different health care providers and institutions at varying stages of the care seeking journey. The respondents' views on strengths, weaknesses and their evaluations of services that they received were sought. At times they were asked to compare services that they received from different providers and institutions. Interviews lasted anywhere between 30 minutes to 90 minutes.

Given the breadth of data collected, not all of it could be used for the purpose of writing the thesis. Selected cases that succinctly bring out overall and important perceptions of quality have been used to write the chapters. Some cases have been used extensively while others very briefly. Care-seeking journeys that cover routine health care experiences and illnesses, emergency health care experiences, surgical care experiences, maternal and child health care experiences, and some uncommon and complex illnesses like paraplegia have been chosen to this end. This helped in avoiding repetition of similar issues that may have been raised across respondents.

Most of the care seeking journeys covered here involved experience with multiple levels of institutions from public and private sectors and contained accounts of patients, attendants, family

members and sometimes friends or neighbours, bringing out a wide range of issues relevant for understanding community perspectives and expectations about quality in health care.

While analyzing collected data there was the option to organize and present the data with an analytical frame where each issue relevant for understanding the phenomenon of quality is discussed in detail and illustrated using relevant field data of care seeking journeys of respondents. Each care seeking journey brought out many issues which could be understood well by invoking and discussing the relevant field data with some information about its context like nature of illness, past experience of seeking care, and outcomes of that care seeking journey. However, using this analytical approach and discussing emerging themes relevant for understanding perception of quality would have led to repetition of cases and its details. Also, the result would have been similar to the existing literature on quality using patient satisfaction and community perceptions (though very meager literature is available).

The available literature on patient satisfaction or perception of quality in health care shows that usually there is a quantitative estimation of the extent of distribution of predefined/selected themes relevant for quality in the community/study population. The themes selected are usually from an existing quality assessment framework or index with predefined components. These themes are, no doubt, important and pertinent to quality in health care. These quality frameworks and indices are typically based on research from some other sector like manufacturing sector, the service sector, retail business etc. or are from some other country.

In this research, the attempt is to avoid repeating similar research approaches by not using existing or pre-decided themes and studying them in a community for its distribution and operation in the study population. This study attempts to bring out people's perceptions of quality of health care to gather themes that they consider important and relevant. It studies care seeking journeys of ordinary people to understand how they think about quality of health care while taking actual decisions about health care to be sought, and when later reflecting on their care seeking journeys.

The narrative of practical experience was used to capture and interpret how people perceived quality of health care. Different phases/ parts and aspects of care seeking journey were analyzed to bring out issues/themes relevant for quality in health care.

In this approach of using narratives of health care seeking journeys for understanding perceptions of quality, different people's experiences for various illnesses from different health care institutions are used and each phase of that journey is examined for what it offers to understand concept of quality of healthcare. In some cases, each phase of care seeking brought out different issues relevant for quality and in others, alternatively the same issue emerged from different phases of care seeking. Therefore, the attempt to discuss issues in quality at different phases led to some repetition of same cases being discussed in various phases or in relation to different components of quality. Attempts to highlight these issues in relation to various levels of care in government health services (PHC, CHC, district hospital, medical college hospital) and private health services (GP, nursing homes, polyclinics, multi-specialty hospital) contributed to some repetition of care seeking experiences.

Organizing the chapter based on the themes that emerged on community perception of quality from care seeking journey would have some strengths and weaknesses. The strength being that relevant themes of quality are discussed in detail. However, discussing each theme/component of quality in relation with part of care seeking journey would have demanded some relevant contextual details like nature of illness, social context, past experience, and outcome to make better sense of the theme. With each theme these contextual details would need repetition along with relevant part of care seeking journey. Another problem of this approach was that, it would give an impression or would be similar to most of the available literature where pre-decided themes (usually from some quality framework or index) are studied for their extent and distribution in study population.

The other option was to organize the chapter by care seeking journey experience. This approach also has its problems and advantages. The problem being that the themes relevant for quality, which is the main objective, would remain dispersed in the entire chapter and need careful reading to identify. However, all these themes could be brought together in a summary. The advantage of this approach is that it reports the findings as they emerged in the study and in people’s care seeking journeys as against giving an impression of being imposed through the study approach. This approach also allows a reader to get sense of entire care seeking journeys of different respondents, albeit fragmented and covered in different parts of the chapters. With these advantages and disadvantages in mind this second option was chosen for writing the analysis.

In summary, there are various conceptual frameworks of quality and there is lack of consensus on one definition. There is no absolute concept of quality. It is assessed relative to context. Thereby, the illness narratives about health care seeking journeys captured both the context in all its complexity and the patient's chosen care seeking path that reflects what preferences and options they had exercised in particular situations. Going in-depth into why they made those choices indicated the concepts of quality they had used. Subsequent to the experience, their opinion about it was another source for revealing their perceptions of quality.

Chapter 2 Quality in Healthcare: Assessment, Indicators and Determinants

Introduction

Defining quality is indeed a difficult task and definition of quality in healthcare is even more complex. There are different definitions and conceptual frameworks of quality and some of these have already been discussed in the previous chapter. These definitions and quality frameworks are being used in different contexts for health services research as well as for health service improvement. Many countries have been developing different frameworks for monitoring, measuring, and managing the performance of their health systems to ensure effectiveness, equity, and quality (Arah et al., 2003). Beyond generic attempts of health service development there are specific efforts undertaken to improve quality of existing health services that have led to different quality assessment and accreditation frameworks. Examination of these quality assurance, quality assessment and accreditation frameworks offers an additional understanding of the concept of quality and implications of these assessment and accreditation frameworks. This chapter examines existing quality assessment or measurement frameworks and mechanisms to understand the concept of quality in healthcare.

2.1 Dimensions to Assess Quality in Healthcare

There is huge diversity across the world in health conditions and needs of populations and health service systems built to respond to them. The diversities in strengths and weaknesses of different health services systems and in the priorities for their improvement are also context-specific. Hence there are no easy one-size-fits-all-solutions to the question of improving health service systems around the world. The problem is compounded, by the difficulties in defining 'quality' in health care and the lack of a consensus on the concept. Some definitions of quality are supplemented with a list of dimensions that help pin down the concept and operationalize quality improvement in health services.

Quality dimensions proposed by Donabedian are one of the most used, for improvement of to health system performance or quality. He proposed a set of defining attributes also known as Donabedian's 'Seven Pillars of Quality' (Donabedian, 1990). These are,

Efficacy*: the ability of care, at its best, to improve health*

Effectiveness*: the degree to which attainable health improvements are realized*

Efficiency*: the ability to obtain the greatest health improvement at the lowest cost*

Optimality*: the most advantageous balancing of costs and benefits*

Acceptability*: conformity to patient preferences regarding accessibility, the patient-practitioner relation, amenities, effects of care, and cost of care*

Legitimacy*: conformity to social preferences concerning all of the above*

Equity*: fairness in the distribution of care and its effects on health*

'Efficacy', the ability of science and the art of health care to bring about improvements in health and well-being is rooted in the premise that under the most favorable conditions, the best possible care will be provided. Similar to efficacy is the concept of 'effectiveness', which is also concerned with improvements in health. Effectiveness, however, is measured in terms of ordinary circumstances in daily practice, where conditions may not always be ideal. In defining and assessing quality, effectiveness can be measured as the degree to which care attains the level of health improvement that studies of efficacy (e.g. randomized controlled trials) have achieved. Along with health improvements, considerations of costs are pivotal to assessing quality. Donabedian has adopted the terms 'efficiency'- achieving the greatest improvements at the lowest costs, and 'optimality'- relating the cost of care to its benefits, to reflect this idea.

Quality of care is also reflected by the perceptions held by patients themselves as well as the community as a whole. 'Acceptability' encompasses a patient's subjective valuation of effectiveness, efficiency, and optimality as well as the relationship between the patient and provider, the accessibility and amenities of health care. 'Legitimacy' can be thought of as acceptability of care by the general community. This includes concerns at the individual level as well as a responsibility for the well-being of all. The final attribute of quality, 'equity', advocates delivery of care that is not only acceptable to individuals but available and accessible to all and also socially legitimate. Equity is concerned with the just and fair distribution of health care services and the benefits of care to the population.

In the United States of America (USA), performance frameworks, quality assessment and accreditation mechanisms most often use the definition and dimensions given by the Institute of Medicine (IOM). The following table contains influential definitions or frameworks of quality and dimensions of quality complied by Reinhard Busse and colleagues.

Reinhard Busse and colleagues classified these concepts as core, sub and other dimensions of quality of health system performance.

This classification is based on the framework of the OECD Health Care Quality Indicators (HCQI) Project. The framework was developed in 2006, by Arah O.A., for international comparison especially among OECD countries. The HCQI project had identified three dimensions namely effectiveness, safety and patient-centeredness as the core dimensions of healthcare quality. It was further suggested that other attributes like appropriateness, continuity, timeliness and acceptability, could be accommodated within the three core dimensions. For example, appropriateness could be mapped into effectiveness, whereas continuity and acceptability could be absorbed into patient-centeredness. Therefore, these were considered as sub-dimensions of quality in health care. Other commonly referred-to dimensions like accessibility, efficiency and equity were considered to be important goals of health system performance (Busse et al., 2019).

Quality improvement strategies and dimensions of quality vary with the frameworks of quality across countries and organizations. The table below shows dimensions of quality in use in selected countries and organizations that have engaged in concerted efforts at quality improvement and in health system performance.

Table 2.1 Quality Dimensions in Ten Selected Definitions of Quality 1980-2018										
Dimensions	Donabedian 1980	IOM 1990	Council of Europe 1997	IOM 2001	OECD 2006	WHO 2006b	European commission 2010	European commission 2014	WHO 2016	WHO 2018
Effectiveness		√	√	√	√	√	√	√	√	√
Safety			√	√	√	√	√	√	√	√
Responsiveness			√	Patient Centered	√	Patient Centered	√	Patient Centered	Patient Centered	Patient Centered
Acceptability						√				
Appropriateness			√					√		
Continuity										
Timeliness				√					√	√
Satisfaction		√	√							
Health Improvement		√	√							
Other	Patient welfare		Access of care process				Patient preference		Integration	Integration
Efficiency			√	√		√	√	√	√	√
Access			√			√				
Equity				√		√	√	√	√	√

source: (Busse et al., 2019)

Table 2.2 Dimensions of Healthcare Performance Assessments According Countries and Organizations

	UK	Canada	Aus.	USA	ECHI	Commonwealth Fund	WHO	OECD
Acceptability		√				√		
Accessibility	√	√	√	√		√		√
Appropriateness		√	√			√		
Care environment and amenities	√							
Competence		√						
Capability			√					
Continuity		√	√			√		
Effectiveness	√	√	√	√	√	√		√
Improving health or clinical focus							√	
Expenditure or cost							√	√
Efficiency		√	√	√			√	√
Equity	√	√	√	√			√	√
Governance	√							
Patient-centeredness or responsiveness	√	√	√	√			√	√
Safety	√	√	√	√				
Sustainability			√					
Timeliness	√			√				

Source : (Arah et al., 2006). ECHI- European Community Health Indicators.

Apart from these influential definitions and frameworks of quality, scholars have used various dimensions in their research. **Ali Mohammad Mosadeghrad** (Mosadeghrad, 2012) **in his review has put together dimensions of quality used by different researchers as shown in the following table.**

Table 2.3 Dimensions of Quality Used by Different Scholars

Author	No of dimensions	Dimensions of quality in healthcare
Maxwell	6	effectiveness, acceptability, efficiency, access, equity and relevance.
Hulka et al	3	Personal relationship, convenience and professional competence
Thompson	7	tangible, communications, relationships between staff and patients, waiting time, admission and discharge procedures, visiting procedures and religious needs
Baker	3	consultation time, professional care and depth of relationship
Tomes and Ng	8	empathy, understanding of illness, mutual respect, dignity, food, physical environment and religious needs
Camilleri and O'Callaghan	7	professional and technical care, service personalization, price, environment, patient amenities, accessibility and catering
Andaleeb	5	communication, cost, facility, competence and demeanor
Jun et al	11	tangibles, courtesy, reliability, communication, competence, understanding customer, access responsiveness, caring, patient outcomes and collaboration
Hasin et al	5	communication, responsiveness, courtesy, cost and cleanliness
Walters and Jones	6	security, performance, aesthetics, convenience, economy and reliability
John (1989)	4	curing, caring, access and physical environment
Jabnoun and Chaker	10	tangibles, accessibility, understanding, courtesy, reliability, security, credibility, responsiveness, communication and competence

Source: Constructed from (Mosadeghrad, 2012)

The above attributes represent aspects of healthcare that help to determine quality while improving health, conserving cost, and meeting the needs and expectations of individuals and larger society. Though these attributes alone do not provide a definitive solution to the problems in healthcare, they offer a perspective by which to evaluate and align quality in health services. Attributes along with other frameworks are more useful because they incorporate social and

political considerations in the study of health care systems. (Hock, 2005). Though useful, this long and inconsistent list of different dimensions inevitably contributes to the confusion about the concept of 'quality of care'.

2.2 Quality improvement systems in selected countries

Further review of literature examined how different scholars, accreditation organizations, institutes and organizations working on standardization of care, and/ or health systems development have defined the quality of healthcare. An attempt was made to analyze whether these different definitions, approaches and understandings of quality of health care address concerns and issues emanating from the broader principles of public health viz. universality, equity and comprehensiveness, and are in tune with principles of social justice, human rights declarations and right to health and health care.

2.3.1 Measurement, Assessment and Improvement of Quality: UK, Canada, Australia and the USA

This segment examines how national health systems of the United Kingdom (UK), Canada, Australia and the USA approach quality measurement, assessment, and improvement initiatives. A review by O.A. Arah and colleagues (Arah et al., 2003) of quality assessment and improvement initiatives along with an analysis of quality and performance indicators in four countries is presented here briefly below.

United Kingdom: UK has a very strong nationalized, publicly funded and publicly provided health care system. The National Health Service (NHS) was introduced in the UK with the Beveridge report (1942) to ensure universal access to health care. It has a coherent national framework for performance, with a comprehensive set of indicators and targets aiming at six areas of performance. Performance indicators were introduced in the U.K health system in the 1980s, in response to the concern around rising health care costs. These performance indicators used hospital and administrative data as a source for assessment. In a bid to rationalize costs, in the 1990s, the role of General Practitioners (GP) was changed with additional role to make them primary fund holders while health authorities became complementary purchasers. Through this, internal market mechanisms were introduced within the NHS. In the 1990s, professional clinical

audits were the main mechanism of developing, improving and maintaining standards of care operating in the environment of managed internal markets (NHS Executive, 1996).

The modernization agenda introduced by the Blair administration, in 1997, has resulted in an increasing emphasis on quality. Clinical governance took center stage, replacing internal market bureaucracy as the importance of integrated care was highlighted. Clinical governance is a framework through which NHS organizations are accountable for continuously improving the quality of their services and safeguarding high standards of care by creating an environment in which excellence in clinical care is expected to flourish (The Department of Health, 1998).

Under the Department of Health, a national performance frameworks initiative has created -the NHS Performance Assessment Framework (PAF). The PAF uses a 'balanced scorecard approach' for the assessment of performance of the NHS that consists of areas of performance like: (a) health improvement; (b) fair access; (c) effective delivery of appropriate health care; (d) efficiency; (e) patient/ carer experience; and (f) health outcomes of NHS care (Department of Health, 2001). The concept of the balanced scorecard implies that 'the overall set of indicators should give a balanced picture of the organization's performance, reflecting the perspectives of internal management and continuous improvement including outcomes and the users' perspective' (A. Commission, 2000). This is to be reported as a 'performance star' ratings system'[2]. In the NHS PAF, effectiveness is conceptualized in the form of 'outcomes of NHS care' along with the virtues like fair access, timeliness and appropriateness with agreed standards (The Department of Health, 1997; The Department of Health, 2001)

Ten indicators are used in this framework to capture effectiveness of the delivery of health care. Most of these performance indicators (PI) are process and/or outcome measures, emphasizing on desired results and the processes that yield these outcomes (Arah et al., 2003).

The National Service Framework (NSF) initiative was started to set national standards, establish performance measures for judging progress, define models for specific care groups or services, and set up implementation support programs (Mcloughlin et al., 2001). Clinical guidelines and evidence-based assessments of health technologies are provided by the National Institute for

[2] Department of Health's Performance Ratings
http://www.performance.doh.gov.uk/performanceratings/2002/national.html.

Clinical Excellence (NICE)[3]. Other major organizations involved in health care quality improvement include NHS Modernization Agency[4], National Patient Safety Agency[5], National Clinical Governance Support Team, General Medical Council, medical specialist associations, and royal colleges. The new National Clinical Assessment Authority[6] is responsible to addresses concerns over the performance of individual doctors. Accreditation is another important quality tool in the UK NHS and its initiative, Improving Working Lives Standard, is designed to create work conditions that equip NHS staff with skills to improve patient service (Arah et al., 2003).

Canada: The Canadian health care system is a large and complex system having federal, territorial, and provincial divisions of health service system. Health care financing is mixed but it is primarily a publicly funded ('Medicare') system that covers virtually all the costs of medically necessary physician and hospital services as well as homecare services. A series of reports from the Royal Commission and Task Force advocated health care reform across Canada in the 1980s (Canadian Institute for Health Information, 2001).

Canada has a coherent national framework, with indicators for health and health system performance. In order to assess the health status of the population and performance of the healthcare system, a new initiative called the Canadian Health Information Roadmap Initiative Indicators Framework was started in the year 2000. Health indicators framework used here covers four dimensions viz. (1) health status; (2) non-medical determinants of health; (3) health system performance; and (4) community and health system characteristics. Various aspects of health system performance are covered in later two dimensions. This approach is based on a population health model and uses a common approach to assess population health and healthcare system.

The 'Roadmap Initiative' to improve quality, utilization, comparability, information dissemination, and functioning of the health system consists of eight domains of health system performance which include: (a) acceptability; (b) accessibility; (c) appropriateness; (d) competence; (e) continuity; (f) effectiveness; (g) efficiency; and (h) safety (Canadian Institute for Health Information, 2000), (Accreditation, 1996). These dimensions, except acceptability,

[3] National Institute for Excellence, http: //www.nice.org.uk.
[4] The NHS Modernization Agency, http://www.executive.modern.nhs.uk/default.aspx
[5] National Patient Safety Agency, http://www.npsa.nhs.uk.
[6] National Clinical Assessment Authority, http://www.ncas.npsa.nhs.uk/

competence, and continuity, appear to be supported by several PIs (Arah et al., 2003). Canada provides comprehensive and regular reports on health programs and services, including 14 specific indicators spanning health status, health outcomes, and quality of service.

This framework assists healthcare providers, managers and other decision-makers to make the right decisions at the right time and the right place. With its activities like consultations, surveys, health education and promotion, and community-based care initiatives this framework gives adequate importance to patient's perspectives. Here, quality in health care is viewed as a multi-dimensional and a multi-perspective concept. Quality improvement initiatives involve two basic strategies: continuous quality improvement and certification/accreditation (Harrigan, 2000). Continuous quality improvement is used as an internal management philosophy that focuses on processes of healthcare and its delivery, consumers, continuous monitoring of quality, education, devoted management, and long-term commitment to effect strategic improvement in quality.

The Canadian Council on Health Services Accreditation (CCHSA) has introduced the 'Achieving Improved Measurement' (AIM) accreditation program to boost quality improvement in four dimensions: responsiveness, system competence, work life, and client/ community focus. The PIs are used as a guide to monitor, evaluate, and improve service processes, outputs, outcomes, and hence quality of care.

PIs used here are mostly process and/or outcome measures. Structural indicators emerge from the part of the framework concerned with community and health system characteristics when one includes the categories of health services and resources. Some of these indicators also capture domains of accessibility and appropriateness, as reflected in indicators like 'age-standardized acute care hospitalization rates for ambulatory-care-sensitive conditions' (Arah et al., 2003).

Australia: Australia is characterized by an established universally accessible national health care system, within a federated structure where funding, delivery, and regulatory responsibilities are shared by the national and state governments (Health & Health, 2000; Welfare, 1999; Care, 2000). In the decade of the 90s there were consistent efforts by the national and state Health Ministers working with many stakeholders to develop a coherent national framework for assessing the Australian health system (Group, 1996, Group 1998, Group, 1999)(Committee, 2000). These efforts were directed at national quality of care, health outcomes and clinical

indicators. By 2000, the National Health Performance Committee (NHPC) commenced work on the new Australian health performance measurement framework, adapted from the Canadian Health Information Roadmap Initiative Indicators framework (Committee, 2001).

Quality improvement initiatives are considered as an integral part of the Australian national health performance framework, which is based on a health determinants model. It is non-hierarchical but relational, as it pays attention to other contextual variables that may considerably influence health care inputs, processes, outputs, or outcomes. The framework has three tiers; (a) health status and outcomes; (b) determinants of health; and (c) health system performance. In this framework, equity is considered as an integral part of all the three tiers (Committee, 2001).

The framework reports on system-wide performance from population health programs, primary care, acute care, and continuing care services.

Health system performance considers nine dimensions, namely: (a) effectiveness; (b) appropriateness; (c) efficiency; (d) responsiveness; (e) accessibility; (f) safety; (g) continuity; (h) capability; and (i) sustainability. The framework conceptualizes effectiveness of the health system as a performance dimension.

Additionally, tools identified in the Australian health system for quality improvement include: accreditation; strengthening consumer feedback and participation; development of information systems to provide high quality data; promotion of evidence-based practice; supporting health infrastructure; development of health care teams among professional groups; reporting of and learning from adverse events; and introduction of clinical risk reduction programs (National Expert Advisory Group on Safety and Quality in Australian Health Care, 1999).

Quality improvement and safety are the foci of various national initiatives such as the National Health Priority Action Council (NHPAC), acts to improve care through performance monitoring in specified disease diagnosis and management, the newly formed National Institute of Clinical Studies, (NICS) independently promotes best evidence practices using effective implementation strategies, and the Australian Council for Safety and Quality in Health Care (ACSQHC) directs and reports on national data usability, quality improvement, and safety issues (Arah et al., 2003).Other non-governmental agencies working on quality of health care include the Australian

Council on Health Care Standards which undertakes performance assessment and accreditation[7] and the Quality Improvement Council, which promotes quality through its Standards and National Review and Accreditation Programs[8]

Quality of care indicators are being developed, as part of an integrated national agenda, to converge with the health system performance framework. Indicators for the 'effectiveness (achieving the expected or desired outcomes within the proper time frame)' dimension are drawn mostly from the prevention and early detection performance areas of population health. These measures tend to be output and/or outcome, or in the short-term, process indicators. Operationally, the 'effective' dimension can subsume the domains of quality, appropriateness, access and timeliness (Arah et al., 2003).

The Australian, and to a large extent the Canadian, frameworks pursue a more relational concept of health and health system – an informational, health determinants model. This model, from Lalonde, makes allowance for the role of the socioeconomic environment, genes or host's constitution, lifestyle, and health care (system) in determining health. If these factors are not considered when frameworks and PIs are developed for monitoring health vis-à-vis health system performance, one runs the risk of spurious conclusions about the relationship between health and health care (or more narrowly medical care) (Arah et al., 2003).

USA: The USA has a pluralistic, decentralized health system with mostly private (largely employer-based) funding and variable state and federal regulation (Mcloughlin et al., 2001). The Federal Medicare public insurance program caters only to the elderly (over age 65 years old) and the disabled, while the federal-state Medicaid program covers low income and disabled persons. The numerous health care plans and networks mostly in the private sector, operate in a competitive market environment where patients and health care purchasers make their selection based on performance information (or quality) and economic grounds (or cost).

At the national level, the US has several health system performance framework initiatives. Firstly, in the IOM proposed framework for national system improvement, effectiveness refers to 'providing services based on scientific knowledge to all who could benefit, refraining from

[7] Australian Council on Health Care Standards, http://www.achs.org.au/
[8] Quality Improvement Council, http://www.latrobe.edu.au/aipc/about.htm.

providing services to those not likely to benefit (avoiding overuse and under-use)'. It outlines six performance domains: (a) safety; (b) effectiveness; (c) patient-centeredness; (d) timeliness; (e) efficiency; and (f) equity (Delivery et al., 2001). Secondly the National Health Care Quality Report has a conceptual framework for measuring the performance improvement of the US health system in its provision of high-quality care. The framework addresses two main dimensions: health care quality and consumer perspectives on health care needs. Components of the healthcare quality dimension are: (a) safety, (b) effectiveness, (c) patient centeredness, and (d) timeliness. Consumer perspectives on health care need to include reasons for seeking care: (a) staying healthy; (b) getting better; (c) living with illness or disability; and (d) coping with the end of life (Delivery et al., 2001).

According to the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), an accreditation organization, *effectiveness* is 'the degree to which the care is provided in the correct manner, given the current state of knowledge, to achieve the desired or projected outcome(s) for the patient[9]. Widely used, but non-national, performance reporting initiatives are from the Consumer Assessment of Health Plans Study (CAHPS) and the Health Employer Data Information Set (HEDIS®) (Reilly et al., 2002).

The National Quality Measures Clearinghouse™ (NQMC™) is a national repository of indicators maintained by the Agency for Health Care Research and Quality (National Quality Measures Clearinghouse™, http://www.qualitymeasures.ahrq.gov/). Many effectiveness-of-care indicators found in the NQMC™ and Health Employer Data Information Set HEDIS® are widely used at the level of managed care plans or health networks. These PIs are predominantly process and outcome measures, as the national framework avoids structural indicators, citing the weakness of the links between most system structures and outcomes of care. Thus, the framework aims to link performance to system targets via its functions (Delivery et al., 2001). The use of PIs to foster actual overall performance improvement in the US health system is predicated largely through mechanisms such as public reporting of quality in the public domain and economic accountability (Leatherman, 2002; Leatherman & McCarthy, 1999).

[9] National Quality Measures Clearinghouse™, http://www.qualitymeasures.ahrq.gov/

Thus, these countries seem to use mainly public health issues and priority areas of health care as proxies for health system objectives, perhaps reflecting an endeavor to link public health and health services within health system performance. Moreover, priority health conditions such as diabetes, coronary heart disease, and cancer reflect the known health service strengths as well as the epidemiological needs of these industrialized nations. Nevertheless, the distinction between public health (with the wider issues of population health determinants) and health services (with the narrower issues of clinical care and cure) should be made clear, articulating their relationship to the overall health system. Furthermore, most of the indicators of effectiveness in the frameworks of these countries are geared more towards measuring outcomes rather than assessing processes (Arah et al., 2003).

While the correct relationship between health care effectiveness and improved health outcomes remains unsettled (Giuffrida et al., 1999; Navarro, 2001). different stakeholders still have different views as to what processes or outcomes should be measured and how? (Eddy, 1998; Thier & Gelijns, 1998). A mixture of PI types may be more useful to assess effectiveness from various stakeholder perspectives.

2.3 Trends in the Concept and Focus of measurement of Quality of Health Services in USA in the 20th Century

Assessment of quality of health care for accreditation developed as a formal system in the USA in the 1950s and was further strengthened with the emergence of private insurance companies and social insurance programmes such as Medicare and Medicaid. Trends in the evolution of the concept and focus of quality assessment of health care services has shown that throughout US history there has been a shift of focus from outcome to structure to process and then eventually back to outcome again.

In the UK, in modern times, Florence Nightingale was the first to notice the positive correlation between introduction of adequate nursing care to wounded soldiers and decreased mortality rate among this group. This observation triggered her interest in studying the relationship between quality of care and positive outcomes. She started looking at the extent of service utilization and their impact on outcomes. She was the first person to write several quality criteria or standards in nursing care.

In the USA in 1910 Abraham Flexner (Flexner et al., 1910) pointed out that education of physicians was directly related to the quality of care. It should be noted here that emphasis shifted from outcome elements to structural elements, i.e., human and physical resources. Hence, education, certification and licensing became important issues.

In the 1930s access to health care dominated the trend in global events and several activities in different countries emphasized increasing availability and affordability of health services. Most of these events were associated with improving structure related factors of health care, both physical and human. The same emphasis on structural elements continued with the establishment of the Joint Commission of Accreditation of Hospitals (JCAH) in 1952. Most of the standards used for accreditation were structural. According to JCAH meeting of structural criterion was equivalent to providing quality medical care (A.F., 2001).

In the two major amendments of social security, Medicare and Medicaid came to the USA in 1965. In these acts quality of care is promised through emphasis on structural elements (providers and institutions), and to a lesser extent on processes. In 1966, Donabedian (Donabedian, 1966) urged health care organizations to look at all the three dimensions, i.e. structure, process and outcome while monitoring and assessing the quality of health care.

During the early 1970s, in order to control cost and preserve quality, the Professional Standards Review Organization (PSRO) was established. PSRO was the first to emphasize 'process' for assessing quality of care. The Peer Review Organization (PRO) established in 1984, also, followed suit and, concentrated only on processes of health care (A.F., 2001).

Unlike PSRO, membership in the PRO was not limited to physicians, but others could have liberal access to them. With the establishment of these organizations, there was greater emphasis on ensuring and maintaining quality. Trends of accreditation and certification that started, led to stigmatization of professionals and institutes and this trend started affecting providers negatively. The doctor-patient relationship began to erode with physicians losing the trust that encouraged their patients to approach them. They reacted to this development through defensive practice of medicine. Physicians began ordering more diagnostic tests resulting in an increase in costs of health care (A.F., 2001).

In the late 1980s, the focus shifted from the PRO's process-oriented and the JCAH's structure-oriented approach to a renewed emphasis on outcome. To this there was brisk reaction from the professional fraternity, putting forward the criterion of case mix. By the late 1980s, the health sector was looking for alternative ways to measure and develop quality. The trend started shifting from an emphasis on process-related standards, back to outcomes. This trend was augmented by a strong movement of the industrial sector towards a new theory- total quality management. In the quest for better outcomes the healthcare industry accepted the concept of total quality management (World Health Organization, 2004) TQM focuses on process measurement and control as means of continuous improvement. It also includes concepts of product quality, process control, quality assurance and quality improvement. As defined by the International Organization for Standardization (ISO 8402:1994): "TQM is a management approach for an organization, centered on quality, based on the participation of all its members and aiming at long-term success through customer satisfaction, and benefits to all members of the organization and to society"[10]. The approach of TQM addresses the issues of efficiency, effectiveness, performance, accountability, and clinical quality of care but leaves out the important aspect of accessibility. Thus, total quality management does not address the issues involved in broader conceptualization of quality, which is based on a public health perspective.

Concept of assessing quality based on outcome received a further boost with the introduction and funding of the US congress of Agency for Health Care Policy and Research (AHCPR) in 1989. AHCPR has developed about 18 clinical practice guidelines; its emphasis on outcomes for quality assessment is still strong (A.F., 2001). Another area that became increasingly important in the late 1990s was performance management and report cards strategy. Performance management is issuing rewards or punishment based on judgment about quality of care and comparative data. Performance management agencies can be part of central administration or responsible to multi-provider organizations or can be purchasers of health care like Medicare or Medicaid in the USA. Performance management was brought in to give an idea about the quality of caregivers to patients and purchasers. The information is available publicly so as to allow patients and purchasers to make informed choices of their caregiver (World Health Organization, 2004).

[10] www.im.tut.fi/cmc/pdf/TotalQualityManagementAndBalancedScorecard.pdf

As seen in the above discussed countries, accreditation of healthcare organizations has returned in a big way. One country after another is following the United States of America by introducing accreditation as a part of their health care system.

2.4 Frameworks and Strategies of Quality assessment/ measurement/ improvement

Several conceptual frameworks exist that aim at characterizing different aspects of quality or explain the pathways for bringing change in healthcare. These frameworks use different sets of dimensions, as discussed above, for quality assessment, quality assurance or quality management and accreditation. The choice of dimensions in these frameworks affects how health services would be structured, provide services to people and change the health status of populations. In some countries the interventions fall under the category of 'health system performance' and in others the nomenclature used is 'quality of health services'; both these efforts are directed at improving functioning and outcomes of health services. Part of the confusion around the demarcation between quality of care and health system performance originates from the insufficient distinction between intermediate and final goals of health systems and between different levels at which quality can be addressed (Busse et al., 2019).

A 2001 report by the Institute of Medicine, *Envisioning the National Health Care Quality Report*, (Delivery et al., 2001) outlined a conceptual framework for assessing health care quality. It is based on two core dimensions: the components of health care quality and the purpose of health care. The components of health care quality comprise four components: safety, effectiveness, patient centeredness, and timeliness. The purpose of health care reflects consumers' needs for different types of health care across the life cycle: staying healthy, getting better, living with illness or disability, and coping with the end of life. Here equity is considered as a key parameter that cuts across both dimensions and reflects differences in quality of care received by different groups, including members of disparity populations. Most quality measures currently in use represent effectiveness measures. Fewer measures represent the dimensions of timeliness or patient centeredness. Very few assess health care safety and access.

In contrast to other popular definitions of quality in healthcare around that time (including Donabedian's), which mainly referred to medical or patient care, the IOM's definition set the focus on health services in general (as "healthcare implies a broad set of services, including

acute, chronic, preventive, restorative, and rehabilitative care, which are delivered in many different settings by many different health care providers") and on individuals and populations (rather than patients), thus strengthening the link of quality with prevention and health promotion.

Frameworks to assess health system performance by the OECD (Carinci et al., 2015) and (E. Commission, 2014) include healthcare quality at the service level and are concerned with the core dimension of quality. Whereas other elements such as accessibility, efficiency and population health are considered as part of health system performance.

It has been argued that broad definitions of healthcare quality can be problematic in the context of quality improvement. There is overall agreement on some dimensions like effectiveness, safety and patient-centeredness of care. However, there is divergence of opinions on access and efficiency as dimensions of quality. While it is recognized that it is important to address access and efficiency in health systems, it has been argued that it might lead to confusion about the focus of quality improvement initiatives and may distract attention away from those strategies that truly contribute to increasing effectiveness, safety and patient-centeredness of care (Busse et al., 2019).

Scholars contend that it is important to distinguish conceptually between access and quality especially when it comes to quality improvement initiatives because very different strategies are needed to improve access (for example, improving financial protection, ensuring geographic availability of providers) than are needed to improve quality of care (Busse et al., 2019).

Against the backdrop of this debate, this doctoral research study is an attempt to understand how people think about the issue of access and quality and if they make a distinction between access and quality and their notion of quality.

Some of the important frameworks and strategies in use on quality in health studied and compiled by (Panteli et al., 2019) and colleagues have been discussed in the following section.

2.4.1 Donabedian's framework of quality:

Avedis Donabedian's framework of quality proposed in 1966; using the triad of structure-process-outcome for evaluation of quality, is the most referenced work in the discussion on quality in healthcare. This framework has already been discussed in the previous chapter.

2.4.2 Juran's Trilogy:

Another commonly used quality framework is the Lean Six sigma, which originates from Juran's quality trilogy. The Juran trilogy defines three cyclical stages of managerial processes namely (1) quality planning, (2) quality control, and (3) quality improvement. These are often used as principles informing quality frameworks in healthcare and are often used in discussions on healthcare improvement (Juran, 1999). The trilogy outlines three domains or activities that can be addressed by separate quality interventions (Organization, 2018). The three domains are cyclical, and are all essential and complementary for quality improvement. The initial activity-quality planning, includes the product or service development processes in organizations and is now also referred to as 'quality by design'. 'Quality control' deals with minimizing waste and determining the causes of waste in product manufacturing and service delivery. Once the causes are identified, corrective action is taken, the process falls again in the zone defined by the "quality control" limits to further minimization of waste. The quality improvement process implemented concurrently with quality control, involves purposeful action by upper management to introduce new managerial processes in the system of existing managerial responsibilities to create breakthroughs in current performance. A 'breakthrough' in other words, a significant change with results, requires special methods and leadership support. The quality improvement process sometimes requires the upper management to step back and understand the hurdles in meeting the needs of customers and the reasons underlying the current under-performance. Here, *breakthrough means "the organized creation of beneficial change and the attainment of unprecedented levels of performance." Synonyms are "quality improvement" or "Six Sigma improvement." Unprecedented change may require attaining a Six Sigma level (3.4 ppm) or 10-fold levels of improvement over current levels of process performance. A breakthrough results in*

significant cost reduction, customer satisfaction enhancement and superior results that will satisfy stakeholders[11].

Similar to Juran's trilogy, WHO identified three areas of focus of quality strategies namely (1) legislation and regulation, (2) monitoring and measurement, (3) assuring and improving quality. Their application is aimed at different target groups, such as professionals or providers. (World Health Organization, 2008) WHO's framing of quality was with the objective of helping different national governments to assess existing approaches of quality, and design and implement new interventions to improve quality. Inspired by this framing of WHO, (Panteli et al., 2019) and colleagues have proposed a new triangular framework of quality. The three domains in Dimitra and colleagues' framework of quality are 'standard setting', 'monitoring' and 'assuring improvements'. 'Setting standards' involves activities like regulation of inputs, clinical guidelines and clinical pathways. The domain of 'monitoring', involves processes of audit and feedback, certification and accreditation etc. while the domain of 'assuring improvements' concerns with paying for quality and public reporting.

2.4.3 The OECD framework of quality:

The OECD framework on quality, developed with the Health Care Quality Indicator (HCQI) Project was published by Onyebuchi Arah and colleagues in 2006. It is useful for understanding the distinction and relation between 'health system performance' and' quality of health care'.

The OECD HCQI framework was to enable the development of healthcare quality indicators, to facilitate inter-country comparisons. HCQI with its focus on quality of health care sees dimensions of effectiveness, safety and responsiveness as core. These core dimensions are applied across four purposes/ functions of the health service system as identified by the IOM viz. staying healthy, getting better, living with illness and coping with end of life. These four purposes correspond to the categories of patients' healthcare needs described above, i.e. primary prevention, acute care, chronic care and palliative care. This framework clearly makes a distinction between 'quality of healthcare' and 'health system performance' where former is

[11] *(https://www.juran.com/blog/the-juran-trilogy-quality-planning/)*

applicable at the level of healthcare services for patient and later is related to a higher level- health system for people where issues like access, efficiency and cost of care become relevant.

<table>
<tr><th colspan="7">Table 2.4 OECD Framework of Health System Performance</th></tr>
<tr><td></td><td colspan="6">Dimensions of health care performance</td></tr>
<tr><td rowspan="2">Health care needs</td><td colspan="4">Quality dimensions</td><td>Access</td><td>Cost/ expenditure</td></tr>
<tr><td>Effectiveness</td><td>Safety</td><td colspan="2">Responsiveness /patient centredness</td><td>Accessibility</td><td></td></tr>
<tr><td>1 staying healthy/ Primary prevention</td><td></td><td></td><td rowspan="4">Individual patient experiences</td><td rowspan="4">Integrated care</td><td></td><td></td></tr>
<tr><td>2 Getting better</td><td></td><td></td><td></td><td></td></tr>
<tr><td>3 Living with illness or disability/chronic care</td><td></td><td></td><td></td><td></td></tr>
<tr><td>4 Coping with end of Life</td><td></td><td></td><td></td><td></td></tr>
</table>

Source : constructed from (Carinci et al., 2015) and (Arah et al., 2006). Shaded area represent focus area of HCQI project.

2.4.4 The WHO stakeholder strategy of quality:

(Ovretveit, 1992) definition has been used for strategy development in various settings and it states *"A quality health service is one which organizes resources in the most effective way to meet the health needs of those most in need for prevention and care, safely, without waste and within higher level requirements"*. This definition focuses on the way resources are used for better outcomes while invoking three entry points to quality: patient, professional and management quality. This Ovretveit's formulation shapes WHO's perspective on quality in healthcare.

(World Health Organization, 2008) discusses three perspectives on quality in healthcare- (1) 'Healthcare service' perspective; (2) 'System of care' perspective and finally (3) 'Populations' public health' perspective. The first 'Healthcare service' perspective focuses on the quality of services to a patient who is under health care. In this perspective there are three components of quality listed below.

- *Patient quality: the service provides patients with what they want and expect, during and after the service.*

- *Professional quality: the service follows procedures and methods which are thought to be most effective in meeting patient's clinical needs, as assessed by health professionals.*

- *Management quality: the service uses available resources in the best way to achieve patient and professional quality, without waste and within higher level requirements* (World Health Organization, 2008 pp-19).

These three components of quality can complement each other or may be in conflict in different contexts. There can be divergence between patients felt needs and expert assessed needs. Both these at times be in conflict with higher level requirements like legal framework or available resources. Therefore, it is important for quality initiatives to balance these.

Most of the quality assessment and improvement strategies target specific health services. However, many quality problems occur when patients move between services. Hence a wider definition of quality is necessary to consider the system in its entirety.

In the second 'system of care' perspective focus goes beyond what happens to patients within a healthcare service facility and addresses quality of care from and between many services. Patients may be satisfied with the quality of care of a specific service, and unhappy about what happens to them during and after shift to another service. The quality of care for a patient depends on how well the patient is treated within each service including the transfer or referral. It also is shaped by how well coordinated and connected are these specific services. The quality of a health system is more than the sum total of the quality of separate services.

The third 'populations' public health' perspective transcends the earlier two approaches and goes beyond healthcare services offered by healthcare providers and Healthcare systems. It attempts to include peoples with illnesses who can't reach to and obtain health services e.g. homeless, marginalized groups or poor and vulnerable people. It also includes continuity of care to people with chronic illnesses along with health promotion and preventive services. Thus public health system quality is concerned with '*how well combined services reach out and are accessible to people with health needs or at risk (who do not ask for services, but may be in greater need of*

caring, curative or preventive services than those who do use services)' (World Health Organization, 2008 pp-20)

WHO(2008) identified four broad categories of methods of quality improvement. The first methodological approach consists of involving and strengthening the role of patients/consumers and citizens. This consumer approach is implemented commonly through consumer protection or patients' rights regulations. It can also be done by involving patients and communities in improving safety and quality in different ways.

The second approach focuses on regulatory and assessment frameworks for health professionals and services. Dedicated regulatory agencies (governmental or nongovernmental organizations) can offer accreditation and licensing services for providers. In some countries the accreditation and performance assessment and report cards are made public to facilitate informed decision making by patients.

The third methodological approach consists of developing different standards and guidelines for various aspects of health care, and applying them. The implementation of standards and guidelines requires systems to supervise and encourage compliance to the prescribed standards and guidelines. Health care organizations usually use accepted standards or guidelines developed by national or international bodies.

The fourth methodological approach is quality problem-solving teams. These teams work on specific problems using specific 'quality tools' which they are trained in to use.

The choice of methodological approach or combination of approaches would depend on the contextual realities and nature of problems at hand. It also depends on whether the objective is to address a specific focus area of health services or to take into account the whole system. It also depends on the assessment of what are the causes of unsafe and poor quality care and whose cooperation would be needed to address that problem. That makes identification and working with stakeholders of the health system essential for quality strategy. The stakeholders are important targets for quality interventions. WHO (2008) identified stakeholders of a national quality and safety strategy to be (1) professionals, (2) health care organizations, (3) medical products and technologies, (4) patients and (5) financers. Possible strategies of quality

intervention for these target stakeholders are different (Organization, 2018; World Health Organization, 2008), (Panteli et al., 2019).

Strategies of Quality Improvement for Stakeholders: Health professionals, Health care organizations, Medical products and Technologies, Financers and Patients

Health professionals such as physicians, nurses and allied health professionals are crucial for delivering health care. Health professionals are oriented to quality improvement through strategies like professional regulation and licensing, certification/revalidation, training and continuous medical education, establishing a patient-safety culture, clinical guidelines, clinical pathways, clinical audit and feedback, explicit description of professional competencies, quality-measurement, peer-review, setting of norms and standards for professional misconduct, medical workforce planning, task-substitution, introduction of new professions and pay-for-quality.

Health care organizations such as hospitals or health care centres are settings where health care is provided through a combination of professionals, medical products and technologies. The quality strategies for organizations include regulation and licensing, quality indicators of organization, external assessments- accreditation, certification, electronic health records, risk-management, adverse event reporting, quality improvement and safety programs, accreditation of integrated delivery systems, organizational innovation, pay-for-quality etc.

Medical products and technologies applied in health care delivery include pharmaceuticals and medical devices, instruments and equipment. The strategies relevant for medical products and technologies include regulation and licensing of technologies (pharmaceuticals and devices), regulation and monitoring of risks and adverse events, health technology assessment and an overall national innovation strategy.

Patients based on their understanding of illness and diseases use various products and services provided through the health care organization with the intention to stay healthy, to get better and/or to prevent further disabilities or discomfort. The quality strategies applicable at patient level include - legislation on patient rights, patient/community participation, systematic measurement of patient experiences and patient satisfaction, public reporting and comparative benchmarking of health care providers and organizations.

Financiers or payers of services include private agencies, government, insurers, employers etc. They can have a major impact on how the healthcare system functions and how national quality and safety strategies work out in practice. The financing of health care can constitute an important incentive or disincentive towards quality. The strategies of quality applicable here include valuing quality in monetary terms, production of quality information, pay-for-quality, initiatives and the issuing of national quality reports.

Clear identification and distinction between targets of quality strategies is important at different levels of decision-making; regulatory mechanisms and planning and designing of strategy. The implementation and monitoring of the strategies varies depending on the target (Panteli et al., 2019; World Health Organization, 2008).

The Plan-Do-Study-Act (PDSA) strategy:

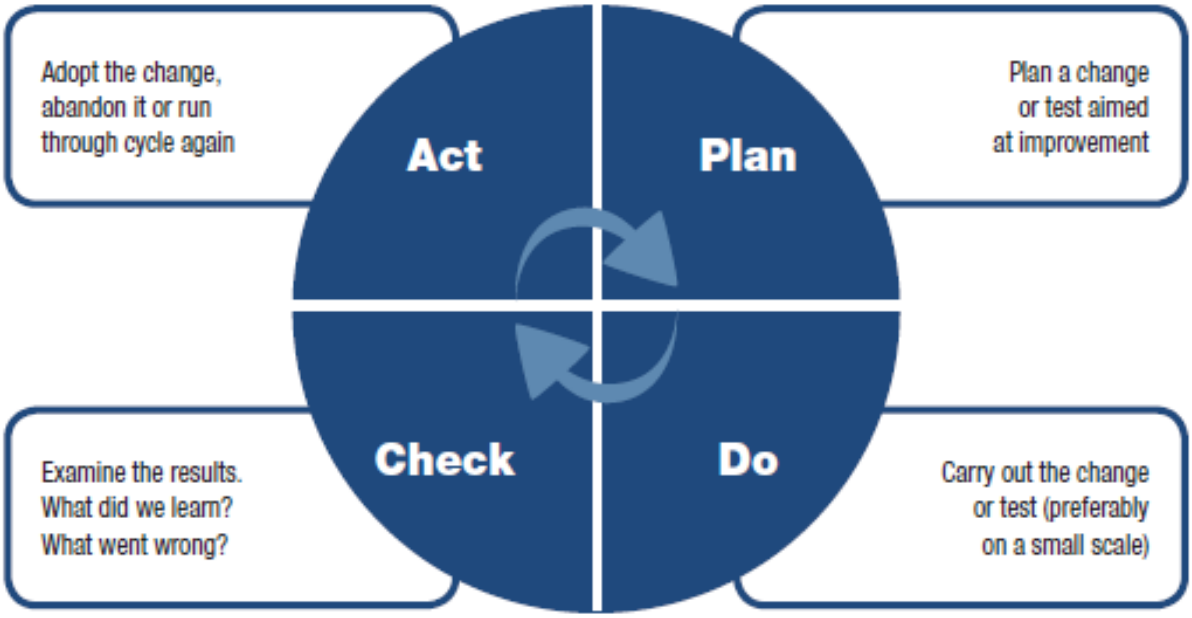
The PDSA model first emerged in the industrial sector, originating specifically from Walter Shewhart and Edward Deming's description about iterative processes for catalyzing change[12]. The cyclical model guides users through a four-stage learning approach to introduce, evaluate and progressively adapt changes aimed at improvement (Taylor et al., 2014).

PDSA cycle focuses on the crux of change- the translation of ideas and intentions into action. The PDSA cycle and the concept of iterative tests of change are central to many Quality Improvement (QI) approaches, including the model of lean six sigma3 and total quality management. It offers quick learning of whether an intervention works in a particular setting and provides for making adjustments accordingly to increase the chances of delivering and sustaining the desired improvement. In contrast to controlled trials, PDSAs allow new learning to be built into this experimental process. If problems are identified with the original plan, then the theory can be revised to build on this learning and a subsequent experiment conducted to see if the new intervention has resolved the problem, and identify if any further problems need to be addressed. Thus, PDSA provides a structured experiential learning approach to testing changes. However, this simplicity also creates some of the greatest challenges to using PDSA successfully. Users need to understand how to adapt the use of PDSA to address different problems and different stages in the life cycle of each improvement project. A well-conducted PDSA promises learning,

[12]Will benefit from a brief description

but it does not, and cannot, promise that users will achieve their desired outcomes (Reed & Card, 2016).

Figure: 2.1 PDSA cycle



Source: (Panteli et al., 2019).

It is one of the most influential frameworks used to conceptualize approaches for the improvement of quality – not only in healthcare but in many industries (Reed & Card, 2016).

The PDSA cycle has been applied by many healthcare institutions and public health programs.

2.4.5 The five-lens framework of healthcare quality strategies:

Dimitri Panteli and colleagues' (Panteli et al., 2019) 'Five Lens Framework' integrates five different quality frameworks and strategic approaches in a complementary manner, not representing hierarchal order. Their combination enables a comprehensive view of quality in health care and offers an actionable picture of different quality strategies

Figure (No.2.2) shows the approaches, –from the innermost to outermost:

1. The three core dimensions of quality: safety, effectiveness and patient-centeredness of IOM.

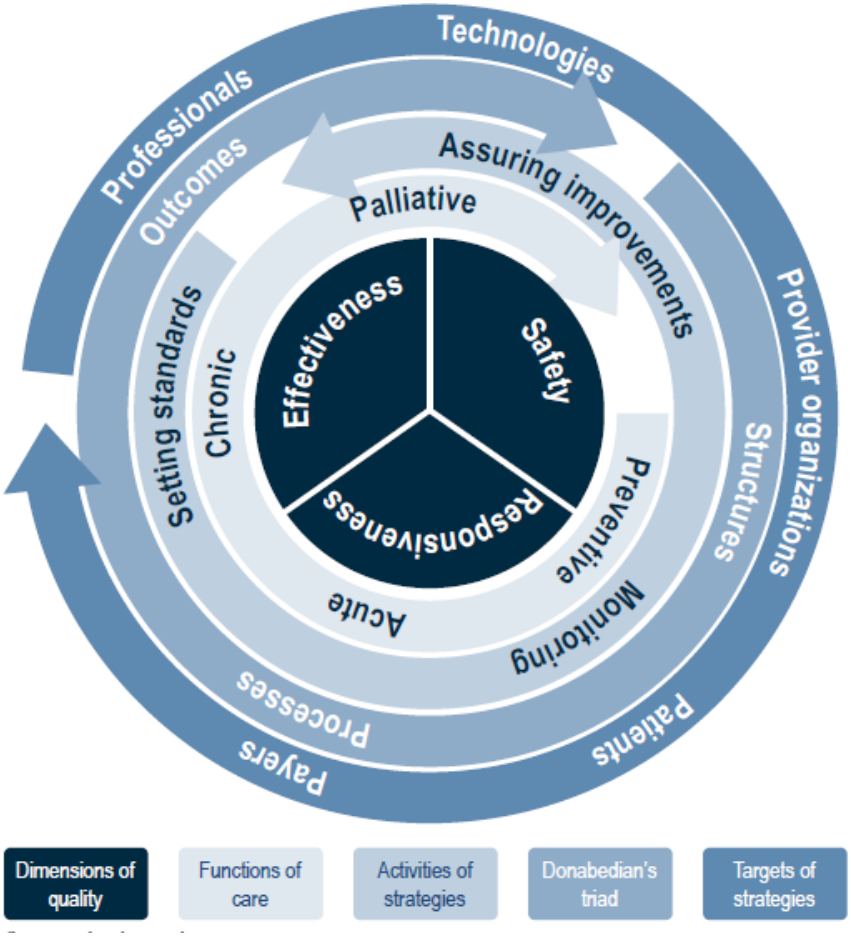
2. The four functions of health care: primary prevention, acute care, chronic care and palliative care from OECD framework.

3. The three main activities of quality strategies: setting standards, monitoring and assuring improvements from Juran's trilogy.

4. Donabedian's triad: structures, processes and outcomes.

5. WHOs five stakeholders and targets of quality strategies: health professionals, health technologies, provider organizations, patients and payers.

Figure: 2.2 Five Lens Framework of Quality in Healthcare



Source: (Panteli et al., 2019)

The authors highlight that 'the conceptualization of the framework in terms of concentric cyclic arrows indicates that different strategies combine different features on each lens. However, in general, strategies do not fall unambiguously into one category per lens of the framework – and there are also areas of overlap between different strategies' (Panteli et al., 2019). It helps us in having a better and relative sense of different quality strategies and their scope and limitations quality assessment/assurance/ improvement.

2.5 Quality strategies according to their level of operation:

Having an understanding of these quality strategies and their relevance for different levels of healthcare is important for avoiding confusion about scope and boundaries of quality

Table: 2.5 -Important Quality strategies and Their Level of Operation

System level strategies	Organization Institutional level strategies	Patient /community level interventions
Legal framework for quality assurance and improvement	Clinical quality governance systems	Formalized patient and community engagement and empowerment
Training and supervision of the workforce	Clinical decision support tools	Improving health literacy
Regulation and licensing of physicians and other health professionals	Clinical guidelines	Shared decision-making
Regulation and licensing of technologies (pharmaceuticals and devices)	Clinical pathways and protocols	Peer support and expert patient groups
Regulation and licensing of provider organizations/institutions	Clinical audit and feedback	Monitoring patient experience of care
External assessments: accreditation, certification and supervision of providers	Morbidity and mortality reviews Patient self-management tools	Patient self-management tools
Public reporting and comparative benchmarking	Collaborative and team-based improvement cycles	Self-management
Quality-based purchasing and contracting	Procedural/surgical checklists	
Pay-for-quality initiatives	Adverse event reporting	
Electronic Health Record (HER) systems	Human resource interventions	
Disease Management Programs	Establishing a patient safety culture	

Source: (Busse et al., 2019).

improvement and health system performance frameworks. The table 2.5 gives some of the important quality interventions according to their level of operation.

2.6 Assessment of quality measurement Sources and Indicators

Quality measurement includes assessment of structural measures, health care processes (what was done), outcomes (what was achieved). It evaluates the capacity to do what needs to be done. Process measures can be further categorized as measures of underuse (when patients do not receive care that is indicated based on their medical condition), overuse (when patients get services that are inappropriate for their medical condition, subjecting them to unwarranted risk and/or expense), and misuse (when a service is provided in a technically incorrect manner). Most of the quality measurement indicators relate to underuse of services considered medically necessary and its comparison (Docteur & Berenson, 2009).

Quality is measured objectively (comparing with agreed standards and guidelines) as well as subjectively (involves patients' expectations or experiences). Measurement uses empirical data like administrative and medical records, perceptions of those involved in health care (surveys, testimonials). Quality if measured with reference to different populations allows one to see whether and how differences in health care gives rise to disparities in health status.

2.6.1 Data sources for quality measurement:

There are four sources or approaches for gathering information on quality (Roemer et al., 1988) involves the analyses of: 1) normal recordings and reporting procedures (including supervisor's report. 2) special studies of health services. 3) patient surveys. 4) Household surveys.

1. Analysis of the normal recordings and reporting procedures (including supervisor's report.) Quality assessment may become part of the basic health information process.

   Information on resources/ structures, processes and outcomes collected as routine can be analyzed to gauge quality. Normal recording and reporting procedures yield data pertaining to indicators like- compliance of current manpower allocation with national staffing standards, the adequacy and maintenance of buildings etc.

2. Special studies of health services.

When a special evaluation of health services is being planned, quality should be included as one of the objectives for evaluation. Such studies, when focused on processes, are usually known as medical audits. When these studies address the quality of resources or structure, they are like accreditation procedures.

3. Patient surveys Enable collection of information on human or interpersonal aspects of healthcare quality.

4. Household surveys can collect information on health status, health care coverage, knowledge and beliefs, and also on quality of aspects like health education, nutrition, water supply, sanitation, environment, etc.

2.6.2 Quality measurement purpose and mechanisms:

Converting the theoretical concept of quality into measurable indicators of quality in healthcare is a difficult task. Measurement of quality involves different aspects depending on the exact definition and the context of measurement.

Different indicators assess different dimensions of quality.

Quality measurement differs depending on the concerned function of the healthcare system and purpose of health care intervention like prevention or acute, chronic or palliative care. Quality measurement varies depending on the target or stakeholder of the quality measurement initiative.

Quality measurement serves two major purposes. The first as a '*summative mechanism'* for external accountability and for verification in quality assurance systems. Measurement for quality assurance and accountability identifies and addresses problems with quality of care to assure users of a basic, sufficient level of quality. Quality assurance is used in many external assessment strategies. Assessment ratings may result in providers of insufficient quality ultimately losing their license or certification. Reported rating of such quality measurement is used by people/patients for making informed decisions regarding choice of care providers. Thus, it contributes to developing trust in healthcare services and providers. Therefore, these rating systems require a high level of precision to make sure that detected differences between providers are real (Quentin et al., 2019).

Secondly, quality measurement is used as a *formative mechanism* for quality improvement. Quality improvement involves continuous efforts by the health care providers to better their performance and bring in incremental change. Here quality measurement does not necessarily have to be perfect because it is primarily informative. Indicators have to be actionable and hence are often more process-oriented. The results of quality measurement are used to motivate change in provider behaviour.

Governments and regulators usually prefer quality assurance and accountability. They use quality measurement to assure that the quality of care provided to patients is of an acceptable level, free from harm and is effective. On the other hand, providers and professionals are more interested in quality improvement for identifying areas where they deviate from scientific standards or benchmarks to improve their services. Depending on the purpose, quality measurement systems face different challenges with regard to indicators, data sources and the level of precision required (Quentin et al., 2019).

2.6.3 Assessment of quality indicators:

The indicators in use to assess the quality of health care services could be classified in various ways. The easiest classification is one based on the dimension of quality that they assess. Indicators could be rate-based or count-based. Rate-based indicators, are among those more commonly used. Count-based indicators are usually used to assess the dimension of safety, identifying individual events that are intrinsically undesirable. Indicators of quality could be classified as generic or disease-specific with the former measuring aspects of care that are relevant to all patients.

Quality indicators may also be classified according to the function of healthcare, i.e. preventive, acute, chronic and/or palliative care. Alternatively, they could be patient-based or event-based indicators. The classification of indicators may relate to structures, institutional processes, clinical processes and outcomes.

Indicators related to Structures or resources: Much has been written on quality of health care, particularly on how to improve the 'technocratic' or 'structural' aspects of care (Gilson et al., 1995). Indicators related to structures/resources include availability of infrastructure in the form hospitals buildings, availability of equipment, drugs, chemicals, and reagents, manpower

resources- their number, qualification, level of skill and attitude of different medical, paramedical and supporting staff (Mainz, 2003).

e.g. Proportion of specialists to other doctors, access to specific technologies (e.g. MRI scan), presence of specialty units (e.g. stroke units), physiotherapists assigned to various units.

The structural requirements must have a sound epidemiological basis.

Indicators related to clinical processes: The degree to which caregivers adhere to standard treatment protocols or guidelines during different diagnostic and therapeutic procedures can be considered a direct measure of performance. Richard Lilford et al (Lilford et al., 2004) have suggested that monitoring the clinical process has several advantages over outcome data. They suggest the use of process-related data for quality assessment. The advantages and some issues related to process indicators for quality include the following.

Clinical process-related indicators advocate strict following of protocol. They treat the violation of agreed or evidence based or logic-based standards as a failure. "Who will determine the standards" however, is a question that remains unanswered. While adherence to standards is important, in the health sector, given the differing contexts of the patients, determination and use of the guidelines need to be flexible.

Target for action is inherent in measurements made, so it allows institutions to take action for improving quality. Quality measurement can be made close to the point of delivery of care, which however does run the risk of deception by the care provider, who might change their behaviour while assessing quality.

Clinical process monitoring needs access to information, which is expensive. Each of these projected outcomes also has serious disadvantages and measuring process-data alone will maintain hegemony of professionals while determining quality of health care. So clinical process-related data alone is not useful for determining quality (Mainz, 2003).

E.g. Proportion of patients with diabetes given regular foot care, proportion of patients with myocardial infarction who received thrombolysis, proportion of patients assessed by a doctor

within 24 hours of referral, proportion of patients treated according to clinical guidelines (Mainz, 2003).

Indicators related to Institutional Processes: Quality indicators could pertain to the organization of different health care services viz. preventive, promotive, curative and rehabilitative services in an institution. The organization of different diagnostic, therapeutic, outpatient and inpatient services also affects the quality of care.

The availability and management of human resources suggested by indicators like the doctor-population ratio, nurse-population ratio, doctor-nurse ratio etc. affect the quality of care. The nature and level of coordination between different specialty departments, between medical, paramedical, supporting and administrative staff all affect the quality of care provided in an institution.

Regular maintenance of medical records, calculation of vital statistics and employing medical audits, clinical reviews and morbidity and mortality audits are important aspects of improving quality healthcare services provided by institutions.

In a multilevel system of primary health care, coordination between different levels of care viz. sub-center, PHC, CHC, district hospital with appropriate referral and transport facility also determines the quality of care. Given their interconnectedness, the quality of care at one level is dependent on the quality at other levels. So, the concept of quality is applicable to the entire system, not just at an isolated level.

Indicators Related to Throughput: Throughput measures are process measures that ….

They are based on management data and cover aspects such as waiting lists, ambulance response time, delays in accident or emergency wards measuring administrative and not clinical procedures involved in care. When such data is used in isolation to judge quality, manage the performance and employ the report cards strategy it could lead to corrective interventions which are ineffective or dysfunctional. e.g. stopping the ambulance from entering hospital premises or target zone of performance management so as to reduce delay in patient assessment when patient enters the emergency department; employing of pejoratively termed ‘Hello Nurse’ which will

serve the purpose of immediate personal contact of patients when they enter the emergency department (Lilford et al., 2004) without necessarily affecting the outcome.

Improvements in institutional factors need additional resources and better management of existing resources. Other intervening factors affecting quality of care are morale, motivation, and attitude of caregiver towards the patients. Work cultures and working conditions need to be improved to address stress caused by prolonged duty hours that also affects quality.

Indicators Related to Accessibility: Access to services is affected by physical, financial and socio-cultural factors. It is one of the important components of public health principles. If health services are inaccessible to people, then quality of care is of little use. Banerji (Banerji, 1982) in his study of nineteen villages showed how financial and cultural factors rendered the ANM's services inaccessible for Dalit communities. While improving health care quality the issue of accessibility needs to be addressed otherwise Quality will remain a distant dream for a large section of the socio-economically deprived, if efforts towards improving quality do not address accessibility. Inaccessibility of healthcare services erodes principles of universality and equity, fundamental to public health.

Cost of care is an important factor affecting access to quality health care services. In resource-scarce countries like ours, where 27% of the population lies below the poverty line, cost becomes a very important issue while assessing quality. Quality should not raise the cost of care unreasonably and disproportionately, especially when, the notion of quality emerged as a concern with anxieties around reducing s the cost of care.

Use of Outcome Data for Quality Assessment: The concept of outcome measurement became popular in the decade of the 1980s and 90s with the assumption that the outcome of care is the ultimate measure of its quality (Ellwood, 1997, Epstein, 1990). Outcome data can be patient-rated or externally evaluated/ expert-rated. They may be grouped into intermediate and end results (Mainz, 2003).

Intermediate: e.g. Lipid profile results for patients with hyper-lipidemia, blood pressure results for hypertensive patients

End result: (should be specified for diseases): Mortality, morbidity, functional status, health status measurements, work status, quality of life, patient satisfaction

Outcome data can be rates of morbidity and mortality or they may be measures of the cost of healthcare to the patient. Outcomes can be patient-rated, i.e., patient satisfaction or community-rated, i.e., community satisfaction. As seen in the experience of the many countries, outcome data in the form of morbidity and mortality rates (professional assessment or expert-rated outcomes) are increasingly being used to assess quality, for accreditation and for comparing different health institutions. 'Outcome' tends to be used very narrowly, often limited to death especially in settings like maternity, anesthesia, and peri-operative. It is argued that use of outcome data to compare quality takes into consideration variations due to other causes such that any residual variation truly indicates quality of care. Patients and purchasers, both prefer outcome data, however outcome (expert-rated) data may give a very partial picture of quality given that it is influenced by many factors including definitions, quality of data, patient case mix, clinical quality of care and chance (Lilford et al., 2004).

V (outcome) =V1 (definition and data quality) + V2 (case mix) + V3 (clinical quality of care) + V4 (chance)

Here V is indicating Variance

Definitions of morbidity and mortality in an institution affect the calculation of mortality rates. For instance, acute care death is commonly used for performance management, and used in calculation of death rates, but if one classifies this death as community death (Henderson et al., 1992) or discharges patients early, so that the burden of mortality burden can be shifted (Sirio et al., 1999), the resultant rates used for quality assessment and comparison could present a misleading picture. The denominators taken for calculating different morbidity and mortality rates also affect the outcome indicators and in turn affect the assessment of quality of health care.

The case mix must be adjusted to accommodate similar, comparable cases for an unbiased comparison. Adjusting the case mix is essential while calculating and comparing these rates (Glance et al., 2002).

Assessments of quality of clinical care examine factors in the process of care and how clinicians and managers use resources therein. In sum, variance in outcomes depends upon many factors. Chance includes the unknown factors which at every stage that may influence the outcome.

Given that outcomes are dependent on a number of factors, assessments based on outcomes are less likely to give an accurate picture of the quality of care provided but in fact may result in stigmatization of caregivers. Comparisons using outcome assessments might also be erroneous since the cases may be dissimilar. Outcome data does little to reveal components that need to be addressed to improve quality.

Thomas and Hofer (J. W. Thomas & Hofer, 1998) have shown that overall quality of care has some correlation with the outcome, albeit weak. Hence most hospitals in the highest five per cent for mortality will not be among the five percent providing poorest quality of care and the poorest quality of care will not necessarily result in high mortality. If outcome data alone is used for accreditation, judging quality and for ranking hospitals one would not know whether the poor results are due to difference in definitions, data quality, chance or case mix, (even adjusted rates of case mix are not sufficient) or structural factors or institutional factors. Hence neither does outcome data, when used alone offer insight into the factors responsible for poor results, nor does it help rank by priority, the various options available. However, it does place the responsibility of poor results solely on the care provider. Providers cope with the blame, fear and distrust through dysfunctional behaviour rather than investing in improving quality especially given that the data does not help identify the factors to be addressed or measures to be taken to improve quality (Lilford et al., 2004).

Providers might manipulate data, patients or procedures. For instance, Burrack et al found that high risk coronary artery bypass graft (CABG) patients were most likely to be denied treatment as compared to similar high-risk disease of aortic dissection patients because CABG was under scrutiny of performance management (Burack et al., 1999). In another instance the CABG mortality rate in New York declined from 3.52% to 2.78% between 1989 and 1992; a significant 40% decline, that was attributed to performance management and report cards strategy. The euphoria surrounding this success was short lived with simultaneous reporting that cardiac surgeons were turning away the sickest and most severely ill patients in places where the report

card strategy was employed. Omoigui et al noted that the number of patients transferred to Cleveland clinic from New York hospital increased by 31% after implementation of this performance management and report card strategy and all these transferred patients were having high levels of risk (Omoigui et al., 1996; Werner & Asch, 2005). The report card strategy inadvertently dis-incentivized the selection of high-risk patients for surgery. On the other hand, it was associated with an increase in racial disparities in CABG use, suggesting that surgeons also may have responded to CABG report cards by avoiding patients perceived to be at risk for bad outcomes, such as Blacks and Hispanics. A similar trend was found in Pennsylvania where this was implemented. 63% of cardiac surgeons admitted to being reluctant to operate on high-risk patients (Werner & Asch, 2005).

Hence measurement of outcome data, expert-rated, is neither sensitive nor a specific marker of quality of care. Measurement of outcomes can be useful for research purposes and to detect trends and extreme outliers by organizations. This assessment of quality should not be used for accreditation purposes or comparing hospitals but should be used by hospital administrators to improve the quality of their institutions' services by comparing it with their previous results.

Indicators Related to Patient Rated Outcome: Evaluations of quality that touch upon the demand aspects of the client–provider relationship is harder to address as compared to those related to supply e.g. infrastructure and equipment, adequacy of drug supply, organization of work flow and human resource utilization. The Bruce and Jain framework (Bruce, 1990, Bruce & Jain, 1991, Huntington & Schuler, 1993) identifies interpersonal relations as a key component of quality of care. Comparatively lesser has been written about enhancing and evaluating interpersonal aspects of health care or the outcomes of care. Most of the studies dealing with patient-rated outcomes while assessing and evaluating quality are limited to patient satisfaction studies.

2.7 Patients Satisfaction for quality assessment

With rising consumerism specifically in the decade of the sixties, consumers' views on services became more salient. The concern for patient satisfaction in health care also emerged in this decade. The medical profession faced many challenges-, feminist literature raised questions on values and forms of care, cultural critiques doubted the claims of expertise of the medical

profession (Coulter & Fitzpatrick, 2003). Evidence suggested that patients dissatisfied with care are less likely to comply with advice and to re-attend the health care facility. Hence quality assessment began to emphasize on patient satisfaction (Korsch et al., 1968).

The growing use of social science methods in studies in health care had also shown the importance of obtaining a community's view on health care. (Davies & Ware Jr, 1988). Social research provided an increasingly powerful means of relating the views of patients to specific aspects of their medical encounter. Views of communities about varying types of organization for health care delivery gained currency. Patient satisfaction was also highlighted by marketing and external evaluation (Coulter & Fitzpatrick, 2003). The relationship between dissatisfaction of the patient and continuity of care was increasingly being recognized. As a response, systematic evidence via surveys of the public and users' opinions was collected and viewed as a vital source on quality (Pollitt, 1988).

Sitzia (Sitzia, 1999) has shown that research on people's perceptions on quality of care has increased considerably in the past decade. Nearly all of these are user-perspective studies, that is, they predominantly aim to measure perceived quality of care of those people who have actually visited the health facilities.

Patient-rated outcome is important to take into consideration while determining quality since patients due to past or current use are in a position to determine the acceptability of services. Patient-rated outcomes vary by age, sex, socio economic status and ethnic group and need to be adjusted while assessing quality. A study by Andaleeb (Andaleeb, 2001) in Bangladesh shows that patient satisfaction is dependent on responsiveness of treatment and hospital staff, assurance given by hospital staff, doctor-patient relationships, discipline among hospital staff and the cleanliness of hospitals among other factors.

A study done by Ben Sira has argued that time given to the patient and interest and attention given by the doctor to the patient are important components of the affective behaviour of doctors. It is the primary determinant of overall satisfaction according to the patient's perception. It is a means through which patients judge the technical competence of the health professionals which they may otherwise be unable to evaluate (Ben-Sira, 1980). However, it is also true that the poor rapport and impersonal care is difficult to avoid due to brief stay of patients in the hospital.

In both the North American and European system, patients are critical of poor communication of health professionals. Their criticism focuses mainly on problems of limited or inadequate information sharing along with problems of a range of behaviours by health professionals. Surveys conducted in the United States (Cleary et al., 1991), in Canada (Charles et al., 1994) and in England (Bruster et al., 1994) reported the same patterns in problems and difficulties with respect to communication dominating patient concerns. The failure to convey information to patients in a satisfactory manner was one of the key components of patients' perceptions of poor quality of care, across types of health-care systems. However, it should be remembered that communication in relation to health care is a broader and more complex set of processes than the simple transfer of information. Patients also express widespread dissatisfaction that health professionals failing to allow them to report their concerns fully and on their own terms, not taking a full history of the presenting problem, failing to reassure or provide appropriate advice. Crucially, patients also feel that they are not encouraged to share decision making with the doctor.

2.7.1 Limitations of Patient Satisfaction in quality assessment:

Review papers by Mary Draper and Sophie Hill (Draper & Hill, 1996) have analyzed studies on patient satisfaction and offer a critique of 'patient satisfaction' at conceptual and assessment/implementation levels.

Locker and Dunt (Locker & Dunt, 1978) had suggested that it was rare to find the concept of satisfaction defined. Studies conducted on patient satisfaction could offer little clarification regarding what the term meant, either to the researcher or the respondents. They further suggested that the search for sources of dissatisfaction was the most important aspect of patient satisfaction studies and research. Carr-Hill (Carr-Hill, 1992) is critical of the conceptualization of satisfaction, particularly of it being a unitary concept, arguing that patient satisfaction is a "complex concept that is related to a number of factors including lifestyle, past experiences, future expectations and the values of both individual and society." S/he further argues that as there is no underlying unity to "satisfaction", - it varies with persons and with time even in one person- it is not correct to combine satisfaction scores with various dimensions of care and contexts into one single index of satisfaction. The reductionism, the methodology necessitates,

may rob the collected data of any meaning and collapse people's complex responses to a simple rating of satisfaction.

A review of patient satisfaction research in the USA by Aharony and Strasser (Aharony & Strasser, 1993) concluded that most of the work has been empirical rather than "theory-testing" or "theory-building", and that there were a multitude of methodological dilemmas. They found no standardized approaches to surveying, and little clarity and consistency in understanding the determinants of satisfaction. There is also a question about the standards against which consumers might expect to make judgments about their care. Patient satisfaction surveys rarely inform consumers about such standards (McIver, 1991), so that the question "compared to what?" arises.

It is not known how people evaluate services or indeed whether "satisfaction" is the way people evaluate their experiences of care. Williams (Williams, 1994) has been highly critical of patient satisfaction research which is built on the assumption that satisfaction is an "independent phenomenon". He argues that such surveys force people to actively construct a notion of satisfaction, by forcing them to express their views in terms that are artificial. He avers that patient satisfaction surveys seem to misrepresent what consumers have to say.

Another criticism has been that the pattern of views obtained in survey research reflects normative values surrounding health care. Patients are reluctant to criticize their health care, at least in part because they risk appearing ungrateful and unappreciative (Fitzpatrick & Hopkins, 1983). The report of one Australian state-wide patient satisfaction survey suggests that patients are very forgiving about the shortfalls in their care (TQA Research, 1993) and many writers note the difficulty of getting past the gratitude response (Meredith & Wood, 1994). There are suggestions in the literature, however, that family members and carers may be more critical (Aharony & Strasser, 1993). Favorable views are due to diminished expectations, normative values.

There seems to be no clear relationship between expectations and patient satisfaction. In a review of work which attempted to model a correlation between expectations and values and people's satisfaction with care, Williams (Williams, 1994) noted that, while there was some correlation

found, "very little satisfaction has been explained in terms of expectations and values". They may be related but it is not a simple relationship.

Scott and Smith(Scott & Smith, 1994) show that an aspect of hospital care that may be rated the most dissatisfactory; is not necessarily the one that consumers would wish to change first. They argue that surveys do not ask people to rank particular aspects of the service they value. While some elements of care may be rated very poorly, patients may not always consider these aspects to be critical in improving outcomes.

Aharony and Strasser highlight in their literature review that there had been no studies of a systematic analysis of comments written at the end of patient satisfaction surveys, having noted earlier that open-ended questions produce more negative ratings and comments than closed questions (Aharony & Strasser, 1993)

Depending on whether a hospital is interested in market share or equity concerns; there are contradictions between interests of governments or purchasers on one-side and hospitals on the other. These interests may guide sampling for the study, the inclusions or omissions of particular subgroups of the population to obtain usable information, and the kind of questions asked or information sought through the surveys, all impacting the responses received. The kind of survey that may suit governments to report performance comparisons may not be of greatest use to hospitals(Draper & Hill, 1996)

Patient satisfaction surveys seek the views of only those who have successfully negotiated the process of being a patient and who are not too ill to be excluded from the sample. To date, the main method of obtaining feedback on patient satisfaction has been surveys and these are usually restricted to questionnaires. Questionnaires are not the only, or even the best tool for ascertaining feedback. The methodological complexities of questionnaires are rarely understood. Patient satisfaction surveys seem to misrepresent or have been projected as what consumers have to say. William (Williams, 1994) argued that patient satisfaction research is substantially flawed because of its reliance on insensitive methods of survey research to produce artificially inflated rates of positive satisfaction. He argued, in contrast, in-depth qualitative methods are necessary to obtain more valid evidence, especially in understanding issues for particular groups and populations.

Meta-analyses of patient's views regarding care by (Wensing et al., 1994), Cleary and McNeil (Cleary & McNeil, 1988) also note the relative neglect of patient's views about the impact of care on outcomes. They warn that the impression might be gained from the literature on patient satisfaction that health outcomes are actually a secondary or minor concern for the patients compared to the need to be treated with courtesy and humanity. More generally, the limited attention to patient's views about the content of their care, reflects the broader perception of patients as passively and uncritically accepting in their judgments of these areas. It is found that patients are less likely to be asked about the value of the treatment they receive than almost any other aspect of their experience. This can be elicited when one seeks to study perception rather than studying satisfaction which treats the patients as a passive agent.

2.8 Satisfaction and Perceptions for Quality assessment

Quality versus satisfaction: (Oliver, 1981) summarizes current thinking on satisfaction in the following definition: "[satisfaction is a] summary psychological state resulting when the emotion surrounding disconfirmed expectations is coupled with the consumer's prior feelings about the consumption experience" (p. 27). This and other definitions and measures of satisfaction relate to a specific transaction (Howard & Sheth, 1969). He further argues and uses the transaction-specific nature of satisfaction to differentiate it from attitude. Attitude is the consumer's relatively enduring affective orientation for a product or service. Whereas satisfaction is the emotional reaction following a particular undesirable experience and usually is consumption transaction specific. Attitude is more general and enduring to a product or service and is usually not situation specific. Quality, especially perceived quality is the consumer's judgment about overall excellence or superiority of a product or service (Zeithaml, 1987). It is a form of attitude, related but not equivalent to satisfaction, and results from a comparison of expectations with perceptions of performance. Perceived service quality is a global judgment, or attitude, relating to the superiority of the service, whereas satisfaction is related to a specific transaction (Parasuraman et al., 1988).

There are several examples where users of service are satisfied with a specific service but did not feel the service firm was of high quality (Parasuraman et al., 1985). Olshavsky (Olshavsky, 1985) considers quality an overall evaluation of a product or service, similar to attitude. Quality is a relatively global and enduring value judgment (Holbrook & Corfman, 1985).

Perceived service quality of consumers, emerges from a comparison of their expectations of what they feel service firms should offer with their perceptions of the performance of firms providing the services based on their experience. Therefore, perceived service quality is viewed as the degree and direction of discrepancy between consumers' perceptions and expectations (Parasuraman et al., 1988).

(Parasuraman et al., 1985) studied 10 overlapping dimensions used by consumers in assessing service quality viz. tangibles, reliability, responsiveness, communication, credibility, security, competence, courtesy, understanding/knowing the customer, and access. Further in the year 1988, they worked out five dimensions to assess service quality in the SERVQUAL framework.

SERVQUAL's (Parasuraman et al., 1988, five dimensions include

Tangibles: Physical facilities, equipment, and appearance of personnel

Reliability: Ability to perform the promised service dependably and accurately

Responsiveness: Willingness to help customers and provide prompt service

Assurance: Knowledge and courtesy of employees and their ability to inspire trust and confidence

Empathy: Caring, individualized attention the firm provides its customers

SERVQUAL involves consumer rated assessment of quality and uses discrepancy between consumers' perceptions and expectations to assess quality. It is valuable when it is used periodically to assess trends of service quality. It is more informative when it is used in conjunction with other forms of service quality measurement. It also has potential in pointing out areas requiring managerial attention and action to improve service quality (Parasuraman et al., 1988.

(Bruce, 1990) gave a framework for assessing quality. She highlighting the neglected issues of quality is family planning services gave framework for assessing quality from client’s perspective. This framework consists of six parts 1) choice of methods, 2) information given to clients, 3) technical competence, 4) inter-personal relations, 5) follow up and continuity

mechanisms and last 6) appropriate constellation of services. For practical application of this framework she suggests using three vantage points as suggested by Donabedian namely the structure of the program, the service giving process itself and the outcome of care. Outcome of care is seen in the form of individual knowledge, behaviour and satisfaction with services. She suggests applying the six parts of quality framework on these three components for quality improvement in family planning program.

At times it is possible to use and interpret behaviours, especially health seeking behaviours as their preferences about choice of healthcare provider and healthcare needs. While studying behaviours is useful and important it does not give complete and valid information about experience with the quality of services used.

Banerji and Andersen (Banerji & Andersen, 1963) moved beyond behaviour (as `action taken - not taken') to perception (as awareness). They shifted the meaning of perception beyond just the bipolar `aware - not aware' categories to the more nuanced three levels of awareness – consciousness, worry and action taking. This represents the process of movement covering range from awareness to action. Behaviour and perception are closely interlinked and yet are distinct. Without understanding perceptions, there is little understanding of a particular behaviour and what its impact is on the ill person and the family. Satisfaction deals with the interface between health care delivery and action taken (behaviour). Action taken depends upon many external factors.

Behaviour may not always reflect `perception' or may do so only in a complex indirect manner because of the constraints in putting perceptions into practice. Therefore, inferences drawn on perceptions from behaviour may not always be valid or complete. While perceptions are shaped by the concrete realities and experiences of life in the present, they are also influenced by the experience of others, whether in the past or in another context. Therefore, inferring by placing behaviours in context may also not provide the real or whole view on perceptions. (Priya, 2007 pp-21).

It is also important to understand that consumers do not use the term quality in the same way as researchers and marketers. Researchers or marketers define quality conceptually. The conceptual meaning of quality makes distinction between mechanistic and humanistic quality. Mechanistic

quality involves an objective assessment of product or service. Humanistic (quality) is assessing subjective experiences of people and therefore is a relativistic phenomenon. It differs across consumers depending on their differing contexts (Holbrook & Corfman, 1985). Thus, perception of quality would depend also on the background characteristics of the consumer.

2.9 Patient satisfaction to Community Perceptions

Despite the increased attention to patients' dissatisfaction in health care, it can be argued that there is a very limited level of involvement of the patient in decision making overall. The case made for giving more say to the patients in treatment decision has been challenged. It is believed that allowing more autonomy will increase demand for health care to unaffordable levels. There is a fear that patients will want investigations or treatments that are unlikely to do them any good. patients having a greater say in treatment decisions poses ethical problems for clinicians, could increase health care costs and lead to greater inequalities in access to care, especially if the demands of the most articulate are acceded to. To some extent, these fears are justified. After all, demand for health care has risen as populations have become healthier, better informed, and more empowered. Better information has not led to an increase in people's willingness to cater to their own health needs without resorting to professional help. On the contrary, greater awareness of the potential benefit of medical care makes people want more of it (Coulter & Fitzpatrick, 2003).

Inequalities in access to information about health and healthcare are a feature of most systems, and the tendency for the most -deprived to get the worst deal seems universal. Thus, claims/ felt needs of the deprived section of the population will not be fulfilled. Pressure to provide more patient-centered care and to involve patients in decisions about their care will inevitably lead in the direction of more individualized forms of care. Most likely, the availability of high quality, individualized care will increasingly be a fundamental component of inequality in health services, with more affluent social groups having access to individualized care and the less affluent receiving standardized care (Coulter & Fitzpatrick, 2003).

In a democratic society with its given historical context and under the welfare state, everyone owes communal provision of security and welfare. The state and community recognize that different people have different claims on the community's resources and such claims are not

absolute. The community has to decide the strengths of different claims as not all claims will be equal nor will all claims be able to be met with the resources available (Mooney, 2000).

Sen (Sen, 1992) indicates that if social conditioning makes a person lack the courage to choose (perhaps even to desire what is denied but what would be valued if chosen), then it would be unfair to undertake ethical assessment assuming that s/he does not have that effective choice. He argues "an over dependence on what people manage to desire is one of the limiting aspects of the utilitarian ethics, which is particularly neglectful of the claims of those who are subdued or too broken to have the courage to desire too much".

Under the neo-liberal economic paradigm claims are indeed the strength of function of what one contributes to society by way of economic production. However, the strength of claims is not a function of individual ability to feel, acknowledge and recognize harm (due to non-fulfillment of claims) or the amount of economic production. The strength of claim is determined by the duty owed by the society to the individual harmed. Where the harm and the extent (and strength) of harm is determined by the society rather than by the bad feeling arising for the person harmed (Mooney, 2000). Gavin Moony further suggests that until it is known what good health care is, there cannot be judgment about what is better and until then there cannot be judgment of what is quality. He further goes on to suggest that once health care systems are identified as social institutions, to judge 'good' and 'better' in respect to health care, there is no better place than in the community.

It is important to not only be informed about the preferences of those who actually use the facilities but also of those who do not use them. A documentation of the perceptions of 'non-users' is necessary for policy makers and may shed light on the factors that influence peoples' choice of health care services. Rob Baltussen and Yazoume ye (Baltussen & Ye, 2006) showed that there is considerable variation in perceived quality of care between various dimensions of modern health services, and between users and non-users. Non-users rate the financial accessibility poorly and more so than users, and inadequate payment arrangements (e.g. lack of credit) and costs appear an important barrier to increased utilization.

Community perception is important to assess the accessibility and quality of services (Tabish, 2001). It casts light on the image institutions of health care have in the community. Patient

satisfaction alone is not enough because it doesn't include those who were denied access to health care institutions or those who have stopped using services of particular institutions on the grounds of access, cost or/and quality. To include them, issues of community perception are very important. Involving the community helps understand their expectations and offers insight into the ways in which quality of health care can be improved. To avoid individualized forms of care (known for creating health inequalities) and to evolve a health system and quality assessment measures that would endeavor to mitigate health inequality, a sound understanding of society's perceptions about health, health care, the health care system, and of parameters like effectiveness, performance and quality of health care is needed. Hence, this study endeavors to explore community perception of quality of healthcare services.

Much of the discussion on quality involves different kinds of dimensions, usually linked with health services delivered to the patient. There are different types of 'standards' that focus on health service delivery (like core dimensions of quality) whereas dimensions and standards relevant for population health are usually relegated to health system performance measures and are usually not included in measurement frameworks and initiatives. Standards used to measure quality of care emanate from the dimensions of care under study and values that one uses to judge them. Standards can be either selective or inclusive depending on the selection of dimensions of care for assessment. Selection and definition of the boundaries of dimensions of care the number of dimensions selected, and exhaustiveness with which performance in each dimension is explored while setting standards, affects the quality assessment. Judgments of quality are incomplete when only a few dimensions are used and decisions about each dimension are made on the basis of partial evidence. Dimensions, such as preventive care or the psychological and social management of health and illness, are often excluded from the definition of quality and the standards and criteria that make it operational. The dimensions selected and the value judgments attached to them constitute the operationalized definition of quality in each study (Donabedian, 1966). Donabedian's work contributed the argument that quality cannot be judged by health care professionals alone but must include the patient's views and preferences as well as those of society in general because 'standards' used in quality assessment are heavily influenced or rather come from three sources, namely,

- the science of healthcare that determines efficacy

- the individual values and expectations that determine acceptability
- social values and expectations that determine legitimacy (Sale, 2005)

Thus, quality assessments as well as experience with the quality of services provided are shaped by world views and moral and ethical value frames

2.10 Social Determinants of Quality of Health Care

Though there has been considerable progress over the past decade in the provision of quality health care, health care quality is not equitably distributed throughout the general population. Placed squarely in the realm of human interaction, the way providers perceive the care needed and the care they provide, and the way clients perceive the care they need and are given, depend on complex, socially and culturally constructed needs and expectations, begging the question 'who defines quality?' and rendering quality a relative concept that is influenced by more complex social determinants (Hartigan, 2001). These determinants include gender, caste, class, socio-economic status, race, ethnicity, religion, region etc. Health care consumers who are members of certain groups, termed "discriminated populations/ disparity populations," frequently confront disparities in health care quality relative to the general population. Members of these disparate populations include racial and ethnic minorities, low-income persons, children, women, and the elderly, rural and peri-urban residents, persons with disabilities and chronic illness, and persons near the end of life.

Disparities can be noted across most dimensions of the health care process (effectiveness, safety, timeliness, and patient centeredness) and across most of the four consumer perspectives (staying healthy, getting better, living with chronic illness, and coping with the end of life) (Fiscella, 2003).

The causes for disparities in provision of health care and its quality can be broadly classified into recipient side factors and provider side factors. Recipient side factors can be analyzed at individual and at community levels whereas provider side factors can be analyzed at individual provider and health care system levels. Both of recipient and provider side factors act or mediate through the channel of social determinants of quality or vice-versa and have been discussed below. The causes of gender-based, caste-based, class-based, racial and ethnic disparities in

treatment and health services provided are complex and include patient, provider/physician, health system, and community factors. These factors are not mutually exclusive; they are interdependent and influence each other.

2.10.1 Provider side factors:

The analysis of the provider side causes at individual provider level viz. physician, nurses, physiotherapists, and other paramedical and auxiliary staff which are part of the team in provisioning health care delivery, is important because 'the provision of social services has a strong personal element: the quality of service depends heavily on the attitudes of the providers (gender, caste, class, socio-economic status, race, ethnicity) undertaking it, and is hard to monitor. Service provisioning, furthermore, often involves a position of power over users' (Hartigan, 2001).

Provider/Physician factors influencing quality include attitudes, biases, stereotyping and economic incentives. The attitudes and biases of providers reflect those present in the larger community. Existing studies indicate that gender stereotypes often guide health workers' interactions with male and female clients (D. D. McDonald & Gary Bridge, 1991; Wallston et al., 1983) Gender exercises a powerful influence on health workers' perceptions of clients' health needs, the explanation of the etiology of clients' health problems, and the content of treatment instructions as well as the manner in which the instructions may be framed to male or female clients, and providers' beliefs about why men and women recover or not from health problems (Armitage et al., 1979; Kannel & Abbott, 1984; McFarlane et al., 1986; Tobin et al., 1987; Wallen et al., 1979).

At health system level the large number of personnel, their position in occupational hierarchy, varying levels of skills and duties require a great deal of coordination and cooperation within and across levels. This difficult task gets more challenging with the influence of social hierarchy, that shapes real life situations rendering issues in inter and intra personal relationships among personnel and between the personnel and communities more complex. Social determinants like caste, class, gender, race, ethnicity etc. determine and affect professional and social interaction amongst the health professionals, across different categories and rungs of occupational hierarchy in the health sector and with the patients and community. The nature and quality of these

interactions has a clear influence on nature, effectiveness and quality of health services that are being delivered (Baru, 2005).

Iyer and colleagues (Iyer, 1995) show that despite guidelines for supervision of staff, the quality of supervision is affected by interpersonal relationships, which are determined by socio-economic backgrounds and occupational hierarchies. Their work provides examples from different health care settings including one at a Primary Health Care Centre (PHC) where ANMs belonging to the same caste as the medical officers were given preferential treatment.

The health system is a gendered system in which doctors, traditionally a predominantly male profession in both the industrial and developing world, are more valued and have more control over resources available within the system, than the nurses, usually female. The gendered division of labour within the health sector reflects the general gendered division of labour in the society. It should come as no surprise that the prestige, credibility and decision-making positions in most health systems are reserved for the medical role, not the nursing/ nurse auxiliary role. Data indicate that the majority of health providers in developing countries' public health services are women. They are not doctors. Usually, they are the nurses and nurse auxiliaries.

In India the data on health personnel clearly indicates the social hierarchy being represented in occupational hierarchy. There also exists a clear gender divide among both medical and paramedical workers. Data shows that most of the doctors, occupying top most and powerful places in the occupational hierarchy, are males and belong to the middle and upper caste and class backgrounds. Lower rungs of occupational hierarchy accommodate middle and lower castes and classes, predominantly women. Even at the paramedical staff level, the training, skills and responsibility are different for male and female paramedical workers specifically for multipurpose workers (MPW). The male workers are often given responsibilities like preparing and examining slides, distributing tablets, supervising chlorination and testing of water, follow up visits etc. On the other hand, women workers are trained to motivate cases for family planning, offer advice and distribute iron and folic acid tablets. Thus, they do much of promotive and preventive work with little clinical inputs as compared to male workers. This kind of division of labor tends to reinforce stereotyping of roles within the health services (Baru, 2005).

Health plan factors include size of copayments and deductibles, location of services, cultural diversity of provider staff, gatekeeping mechanisms, use of practice guidelines, and quality improvement activities. In the United States, studies have shown that patient's satisfaction with access and continuity is lower in managed care units, such as health maintenance organizations. Many basic problems in patients' experience of health care can be traced to some aspects of the healthcare system that are increasingly compelled to compete in terms of efficiency, to resort to impersonal routinized forms of care (Coulter & Fitzpatrick, 2003).

In a highly stratified society like ours where position of personnel in the social and occupational hierarchy plays crucial role in determining the nature and quality of interactions both within and outside the health services, Baru (Baru, 2005) advocate addressing human dimensions of health services, consisting the nature and quality of relationships among professionals and between professionals and communities on priority basis, along with addressing the financial and physical infra-structure aspects of provisioning. These observations have two important implications. First for designing and developing a medical curriculum addressing these issues and second is for human-power development for having representation of all sections of society in the health personnel.

2.10.2 The recipient side:

The recipient side causes when discussed at the individual patient-level include the ability to afford insurance or co-payments, knowledge of benefits of care, mistrust of providers and health institutions, and attitudes and preferences for treatments etc.

Community factors include availability and cost of health insurance, reimbursements, strength of safety net provided, and physician workforce distribution. These factors are dependent on each other. For example, physician bias may generate greater patient mistrust and vice versa. Similarly, low insurance reimbursement (e.g., Medicaid payments) may provide incentives to physicians to minimize care.

Recipient side causes for disparity in health care and their experience with health service have been discussed below along with different social determinants of quality.

Gender: Gender constitutes one of these determinants which have a significant influence on nature as well as perception of quality of health services, and has been discussed here briefly. Gender relations between health providers and clients, and between health facility staff themselves, have not been adequately addressed by previous models of quality of care (Abouzahr et al., 1996; Vlassoff, 1994). Haddad et al (Haddad et al., 1998) have pointed out that research on the perceptions of what constitutes quality of care from the viewpoint of male and female health care providers and users has been scarce.

A review of the literature on gender and quality of care (Pittman & Hartigan, 1996) grouped existing research on the subject according to the following four aspects:

- Differences in providers' attitudes toward female and male patients;
- Differences in behaviour and clinical decision-making of providers in caring for female and male patients, including the processes of information exchange, diagnosis, treatment and follow-up decisions;
- Differences between male and female providers' attitudes and behaviour towards patients; and
- Appropriateness of norms and protocols for women, given the biological and psycho-socially constructed differences between the sexes that determine specific health needs.

Litvack and Bodart (Litvack & Bodart, 1993) suggest that clients, particularly women, are more likely to be positive about the health services and return to these when they have been satisfied with the interpersonal relationship established with their health provider, and that confidence and compliance result from such positive interactions, even independent of the objective quality of services provided. Thus, gender is an important factor in determining user perceptions of quality of health care, especially with respect to those aspects of quality that relate to interaction.

Gender disparities in the use of expensive technology have been extensively documented (Raine, 2000). There is clear evidence of worse care for women than for men. Women are less likely to receive appropriate medications such as aspirin and beta blockers following a myocardial infarction, (Rathore et al., 2000) less likely to receive a renal transplant (Kjellstrand, 1988,Garg

et al., 2000) (despite more female donors), and less likely to receive adequate treatment for pain (K. O. Anderson et al., 2000). Many women also experience reduced access to reproductive services. Frequently health care plans do not cover the cost of contraceptive and abortion services, and the latter are not available in many communities.

The literature reveals that while both poor men and women suffer greater ill-health than their more well-off counterparts, ill health and/or the illness of family members generally represent greater burdens for poor women in comparison to poor men. This is because, in addition to resource constraints that affect poor men and women, gender inequalities and inequities place women, in particular, at a further disadvantaged position. The reasons for this are multiple, and interrelated (Hartigan, 1998). In sum, socially constructed characteristics that are attributed to one sex or another at the individual level, or associated with male or female spheres of activity at the societal level, give rise to gender inequities and inequalities and to the perpetuation of gender stereotypes that can enhance, or deter the health and development of men and women, as individuals and as population sub-groups.

The complex construct of gender interacts with biological/ genetic or immunological sex differences to create health conditions, situations or problems that are different for men and women as individuals and as population groups. This interaction, and how it plays out across different age, caste, race, ethnic and income groups, must be understood by health providers and health policy-makers themselves. Given such understanding, more effective and equitable health promotion and disease prevention and control interventions can be developed.

Other determinants influencing quality of health care like socio-economic status, race and ethnicity are discussed below and have been extensively used from the work of Kevin Fiscella et al (Fiscella, 2003, Fiscella et al., 2000).

Socio-economic status: Mediating through poorer housing and nutrition, lower educational and economic opportunity, and greater environmental risk, both lower socio-economic position, race/ethnicity are associated with poorer health and shortened survival (Lantz et al., 1998; Sorlie et al., 1995). Lower socioeconomic position is associated with overall lower health care use, even among those with insurance (Fiscella et al., 1998; Newacheck et al., 1996). Lower socio-economic position is associated with receiving fewer pap tests, mammograms (R. A. Hahn et al.,

1998; Potosky et al., 1998), immunizations, later enrolment in prenatal care (T. P. McDonald & Coburn, 1988) and lower quality ambulatory and hospital care (Brook et al., 1990).

Race: African Americans receive less appropriate treatment for cancers of breast, lung, and less intensive treatment of prostate cancer (getting better) (Klabunde et al., 1998; Shavers & Brown, 2002) fewer anti-retroviral drugs for HIV infection (living with chronic illness) (Moore et al., 1994), fewer antidepressants for depression (getting better) (Sirey et al., 1999), less appropriate management of congestive heart failure (CHF) and pneumonia (getting better) (Ayanian et al., 1999), poorer quality of hospital care (getting better) (Kahn et al., 1994), fewer pediatric prescriptions (getting better) (B. A. Hahn, 1995), fewer admissions for chest pain (getting better) (Johnson et al., 1993), and less adequate treatment of cancer pain (coping with the end of life) (Cleeland et al., 1997). Elderly blacks, compared with whites, are seen less often by specialists (Blustein & Weiss, 1998; Kogan et al., 1993) receive less appropriate preventive care like mammography and influenza vaccination (Gornick et al., 1996), and fewer expensive technological procedures (Escarce et al., 1993). In general, blacks receive less intensive hospital care (Ayanian et al., 1999), including fewer cardiovascular procedure (Ayanian et al., 1993; Goldberg et al., 1992; Peterson et al., 1994; Whittle et al., 1993), lung resections for cancer (Bach et al., 1999), caesarean sections (Stafford et al., 1993) and orthopedic procedures (Romano et al., 1997).

Ethnicity: Compared to whites, Latinas receive fewer mammograms, pap tests and influenza vaccinations, less prenatal care(Collins et al., 1999) and less analgesia for metastatic cancer and trauma (Cleeland et al., 1997). Asian American receive fewer Pap tests and influenza vaccination (Collins et al., 1999). Not surprisingly, disparity in health care use and process are associated with disparity in outcomes. Ethnic minorities report lower health care satisfaction and greater discrimination (Henry, 1999). Hispanics, Asians/Pacific Islanders, and American Indians/Alaska Natives also appear to receive suboptimal care although disparities are smaller than those observed for African Americans (Virnig et al., 2002). Hispanics receive fewer cardiovascular procedures (Carlisle et al., 1995).

Caste: In India doctors are mainly upper caste Hindus, Christians and Parsees. (Banerji, 1982; Madan et al., 1980). In the late 1970s a study on the social background of doctors at All India

Institute of Medical Sciences in Delhi showed that 37% of the respondents belonged to upper castes of which 26% were Brahmins and 11% were Kshatriyas, 49% belonged to the middle castes of which 34% were Vaishyas and 15% were Kayastha. The remaining 16% belonged to the backward classes and schedule castes.

A study on social background of ANMs in Maharashtra in early 1990s by Iyer et al (Iyer, 1995) revealed that two thirds of the ANMs from selected districts were from middle and upper castes. Scheduled castes and scheduled tribes together constituted only a fifth of the workers. Banerji (Banerji, 1982) in his nineteen village study shows that the caste backgrounds of ANMs affect their interaction with different sections of the community. If an ANM is from a lower caste, then families from upper castes treat her with indifference and disrespect. Upper and middle caste ANMs are uncomfortable and sometimes even unwilling to cater to lower caste families. These social dynamics are expressed in the form of rude behaviour or indifference on the part of health workers to the lower caste communities. Quadeer (Quadeer, 1985) in her study on community health workers (CHW) in Shahdol district showed that the caste background of CHWs influenced their interaction with the community.

Fiscella Kevin and colleagues (Fiscella et al., 2000) argue that the pathway through which socio economic factors or social determinants affect health care are complex, and consists of health care affordability (Potosky et al., 1998), geographic access (Heckman et al., 1998; Perloff et al., 1997), transportation (Heckman et al., 1998), education (Pincus et al., 1998; Potosky et al., 1998) , knowledge (Brown et al., 1990), literacy (American Medical Association, 1999), health benefits (Lannin et al., 1998; L. R. Thomas et al., 1997), racial concordance between physician and patient (Cooper-Patrick et al., 1999), patients' attitude (Fiscella et al., 1998) and preferences (Oddone et al., 1998; Whittle et al., 1997) competing demands including work and child care (Lannon et al., 1995), and provider bias (Schulman et al., 1999; Van Ryn & Burke, 2000). The significance of any factor is likely to vary by patient, physician, context and time.

The notion of health care quality implies that resources are allocated according to medical need, risk and benefit. Though these disparities have been extensively documented by different researchers, isolation of these disparities by mainstream quality assurance has impeded progress in addressing them. There has been little discussion on the failure of existing quality assurance

measures to identify socio-economic, racial and ethnic disparities in quality. Current performance measures fail to account for impact of the socio-economic, racial/ethnic composition of members of plan performance (Fiscella et al., 2000). It should be remembered that these disparities in health care delivery are a fundamental threat to the quality of health care services. Unmonitored, these biases in performance reporting could create an incentive for health care organizations to boost ratings through selective enrollment of low-risk members and denying treatment to Blacks or ethnic minorities who are projected as high-risk communities for certain diseases. Recognition of disparities in health care as a quality issue has far reaching implications for reducing socio economic and racial/ethnic disparities in health care. Though health care alone cannot be expected to eliminate socio economic and racial and ethnic disparities in health outcomes, it undoubtedly plays an important role (Fiscella et al., 2000).

Quality measures specific to members of discriminated/unequal/ marginal populations are needed for two reasons: equity and relevance (Fiscella, 2003). First, population-specific quality measures help to ensure that health care is equitably provided. Population-specific quality measures are needed to identify health care disparities that are typically hidden from view by the current reporting procedures. Use of population-specific measures allows for targeted quality improvement interventions designed to eliminate disparities. Second, quality measures developed for the general population may not be relevant to discriminated/marginal populations. The prevalence and health impact of various conditions and types of healthcare needed to treat these conditions frequently differ between groups.

2.11 Conclusion:

Distinct from the manufacturing sector and other industries, health services involve simultaneous production and consumption of services. Therefore, perceptions of both sets of stakeholders in this process are important. Health care providers- health professionals, managers of health organizations, financiers - prefer to focus on outcome of care while assessing quality. The outcomes of healthcare are varied and can be defined in different ways. They are difficult to analyze without the knowledge of the process of care. The judgment on quality of care has a preferential connotation too and is not solely dependent on the objective outcome of care. It is also shaped by expectations, needs and knowledge along with value frames of providers as well as recipients of health services.

The patient's perceptions are important to understanding the quality of care-services delivered. Perceptions of health care providers- with their scientific training and day to day experience of working in health care organizations and interacting with patients and their attendants – are relevant for design, structural and procedural aspects of the health service system. Third party payers on behalf of patients, like insurers would further add to the complexity of defining and understanding quality in health care. An effective system of quality in health care requires perceptions of all the stakeholders like health service users, healthcare providers and third-party payers are taken on board (Harteloh & Verheggen, 1994).

This study attempts to explore the community perceptions of quality of healthcare from rural community especially amongst two different caste groups, of which one is a lower caste (dalit) community.

Chapter-3 Choice of Care Providers and Overall Experience of Care-Seeking

Introduction

3.1 Quality considerations in choice of health care providers and institutions

It is observed that the choice of health care provider and institution is based on different considerations and these are different for different people. Factors affecting choice of health care provider or institution change with nature of illness and need. Routine illnesses, bearable disease conditions gave community members ample room to make an informed choice, demand or expect a better care experience, and change health care provider or institution if experience was not as desired. Life threatening disease conditions or health conditions requiring advanced medical/surgical interventions created a situation where life and wellbeing bore upon reflections on quality much more as compared to other experiences in care seeking.

The village Primary Health Centre was first choice for most respondents seeking care in case of need. If the care provided at the PHC was considered sufficient to address illness then the PHC was the preferred choice, since it was most conveniently located. However, though present in the village, the PHC services were no tavailable on a daily basis, and on the days the services were available, they were offered only for a few hours in the first half of the day. In many cases the treatment offered at the PHC was not effective in addressing the health problem and at times the PHC health workers had advised respondents to seek care from facilities in towns like Kandhar and Nanded offering higher levels of care.

Therefore, illness requiring care beyond functional working hours of PHC called for care outside the village, usually from block town of Kandhar or District town of Nanded. Occasionally care was sought from beyond these two locations. The alternate locations were Mukhed, Loha and Ahemdpur which were block towns having RH/CHC facilities similar to Kandhar town. In addition, for some illnesses,the people of Panshevadi village chose care providers from distant cities of Aurangabad, Pune, Mumbai from Maharashtra and Hyderabad from Telangana.

The respondents sought care in the hope of getting relief from suffering i.e. effective care, at lowest possible costs, in a convenient manner while ensuring self-respect and dignity in the process of seeking care. During the interviews conducted for this research, the answers to the

question on choice of care providers were more reflective as the respondents now had the advantage of hindsight at the end of the entire cycle of care seeking.

Once it was clear the health problem they were facing needed intervention from providers beyond the PHC, there was large range of services and care providers respondents had to choose from. This choice was not always pleasant or voluntary as circumstances had pushed them into looking for other care providers who could address their needs. The respondents had mainly two options to choose from- public sector and private sector facilities. At block town, the only public sector facility available was the RH whereas the town offered a greater range in the private sector- several general practitioners and two small nursing homes. Both the nursing homes were run by gynaecologists and provided emergency obstetric care along with treatment for routine gynaecological illnesses.

In the district town of Nanded, the range of services available was much wider. There were two governments medical college hospitals- one of modern medicine and the other of Ayurveda. There was also a municipal dispensary and an urban health post.; However, none of the respondents had used services from these two health centres. The private sector in Nanded boasted a wide variety of choices like private clinics of GP, speciality and multi-specialty hospitals of different permutations and combinations of specializations.

When respondents sought care in the RH or government medical college hospitals, the choice they were making was that of the institution and not a specific provider. There were however a few cases that chose RH Kandhar to seek care from specific doctors like Dr. Sugadekar and Dr. Pagare- both known as good doctors in the community. In case of private hospitals, usually the choice was because of a particular specialist doctor; very few private hospitals were chosen with the intent of seeking care at the specific institution.

3.1.2 Choice of government healthcare institutions

T**he context of illness** emerged as important factor shaping the choice of health care provider, especially in case of medical emergencies like accidents and injuries. ‘Shambhu *and his friend who was pillion riding bike met with an accident in Mukhed, an adjacent block town. They were taken to the CHC/ sub-district hospital of the same town by people on the road. For such emergency situations usually the nearest hospital is chosen for seeking care. Both of them were*

admitted in the hospital and their family members were contacted. The pillion rider got some abrasions and contusions and was treated with some analgesics, some creams and ointment, and IV fluids. Shambhu with no external injury marks was also put on IV fluids. The doctor at the sub-district hospital advised them to go to the district hospital. After about 3-4 hours, some family friend from his village Panshevadi arrived in the hospital. Shambhu noticed that he could not move both his upper and lower limbs. He assumed that it was due to injury or due to the effect of pain relieving injections. He was then taken to his village Panshevadi in a privately rented car. After an accident the nearest health care provider is preferred who provides first aid and essential medical care. Comprehensive treatment decisions are usually taken after the emergency situation has first been tackled. Thus proximity of the health care provider or institution was one important criterion for choice. Government-run health care institutions are preferred in situations like **accidents and injuries that could pose medico-legal concerns**. Most private health care providers do not take on such cases to avoid potential medico-legal hassles.

Expertise or fame of the health care provider or institution established in popular memory through past community experience and that of friends or kin especially people with similar disease conditions also affected the choice of health care provider. It informed the respondents about what to expect from the services provided, strengths and weaknesses, possible difficulties, and possible outcomes. The choice of a particular provider or institution from a range of suggestions and the basis for that choice, reflects the respondents' preferences and perceptions of quality of health care. The discussion on care seeking journey also had revealed why they changed their care provider.

Popular perception and image of an institution played an important role in shaping choices of care providers. One of the respondents Shambhu- *after spending almost 6 months at home with paraplegia, there was some improvement and his limbs started showing signs of movement, he could move his hand and legs. Then he decided to show a doctor, and after* ***many suggestions from friends and relatives*** *he visited the Government Ayurvedic medical college and Hospital at District Headquarter Nanded where he was admitted for almost 2 months.* The government hospital was known for providing good care to patients with different kinds of paralysis.

While the choice of health care provider is made by taking into account various factors in many instances people hardly have any choice and have to fall back on the only provider providing care. The **lack of choice due to circumstantial conditions** makes for health care journeys that they just have to endure. '*Shambhu and his wife went to the government medical college and district hospital to get treatment for his bed sore, as advised by the medical officer at PHC. At the medical college hospital, he was investigated by X-ray and USG abdomen. He spent almost his whole day in the hospital getting these tests done. In the late evening he was given some tablets, syrup for relieving constipation, and some cream for applying on the ulcer. When he inquired about the possibility and need of doing dressing of the affected area they told him to wash his wound and apply the cream at home. He was told to leave the hospital at that time, late in the night. He had to request and beg the hospital staff to allow him to stay as it was late and he could not get a vehicle so late in the night. He could not afford to spend on a privately rented vehicle. He was allowed to stay in hospital premises but was repeatedly asked to leave the hospital premises before the dawn. He then decided to go to an ayurvedic medical college hospital. Unfortunately, that day was a holiday. He went to the ayurvedic hospital emergency department. Here, he was told that the he would need dressing, some injections, and medicines that cannot be given at an Ayurvedic hospital* (This hospital is known to perform some surgeries and practice modern allopathic medicine for selected conditions. So the refusal of this treatment sounds suspicious*). He was advised and referred back to the medical college and district hospital. Now he had nowhere to go. He spent his whole day on the street along with his wife. By now his wound had worsened with one more opening on the buttock with foul smelling purulent discharge.* ***With none of the government hospitals showing any sensitivity to his suffering and after spending a day on the street he was left with no option but to resort to a private hospital. Given his financial situation, he opted for a trust hospital, which worked on a 'no profit, no loss' basis, Tayar*** *Hospital.*

Shambhu's experience is evidence of the fact that the choice of health care provider or institutions by users is not always an informed or pleasant decision. Often, circumstances are such that they are forced, knowingly or unwillingly, to choose a health care provider or institution due to the refusal of treatment from one institution, often government health care institutions, but sometimes even private institutions, makes individuals change or opt for alternative healthcare providers or institutions. The **refusal of care/treatment and**

partial/incomplete care were some of the important concerns that were articulated in many interviews. These concerns are less likely to be captured if perceptions of quality are assessed from patients in a hospital or clinic setting. It is the community setting that allowed reflection on experiences of seeking care where refusal of care, incomplete/partial care could be articulated with the benefit of hindsight and without moral dilemmas of being ungrateful or fear of consequences regarding future treatment experience.

When it comes to seeking treatment from higher levels with advanced expertise and facilities, the options available are few, and choices get curtailed further, if one takes into account the convenience they offer and the price they charge. This instance of needing surgery is a case in point- *Based on the advice of Dr. Bawadekar they thought that she would need an operation for the removal of her (Mayabai) gall bladder. However,* ***they did not have that much money, so they decided to go to the Government medical college and district hospital.***

Availability of a specialist doctor or health care provider relevant to the health problem affects the choice of health care providers. The seriousness of illnesses also shapes the choice of health providers. Users of health services identify specialization from health providers' educational qualifications or may come to know of them due to the fame specialist doctors may have acquired for their services treating specific health conditions. In rural areas, availability of healthcare providers, especially doctors, is an important concern. Doctors are either not available in the villages or if the they are doing their jobs sincerely; they are available for a few hours on working days. The availability of doctors in rural areas, to address health emergencies, at odd hours is limited and also limits the choices people have when it comes to health care providers. Positive interactions with available care providers at the time of health emergencies, help generate rapport and confidence in that health care provider among community members. In rural areas unless the doctor lives in the PHC village, the emergency health care provider by default is usually a private practitioner. Private general practitioners are generally available in large villages / block towns. *Sulekha's labour pain started in the night at around 11 pm. After waiting for an hour at home, she was taken from her maternal home to nearest PHC to Kurula (PHC village) at midnight. At Kurula, she was taken to a private practitioner, a BAMS doctor.* ***The private practitioner had to be approached because there was no doctor at the PHC.*** *On asking whether a doctor is necessary for a delivery, the father-in-law, who was present there,*

said that ***there was no need for a doctor as such. However, Sulekha's condition appeared serious and she was in pain, so they decided to show her to a private practitioner****.*

Government hospitals are preferred over private care institutions if the cost of care is relatively high, especially for conditions which respondents consider relatively less serious. Most of the time, pregnant women are taken to government hospitals for delivery; since that helps to keep the costs low. Community members found the high expenditures that private hospital services entailed, were unnecessary given that that deliveries were attended even by dais until very recently. Another possible reason behind this could be that the **overall experience of birthing services for the pregnant women might have been better with government institutions as most of the people told that government hospitals are used for delivery services.** Custom dictated childbirth to be the responsibility of the woman's parents. Hence in pregnancy/childbirth-related emergencies, precious pregnancies or first deliveries especially in economically well off families, private hospital deliveries with personalized services became a means for the woman's natal family to showcase their investments in their daughters and grandchildren). In such cases, though few in number, seeking care from a private hospital served the purpose of establishing social status, prestige and making statement of caring for family members. Here the reputation and image of a hospital or doctor was important criterion for people's choice of care provider.

The likelihood of getting rational care is an important consideration in choice of care provider. Respondents took into account the likelihood of getting an accurate diagnosis and better treatment, especially if it was a relatively less common disease or if regular treatment offered by doctors had been ineffective. *The concern for right kind of treatment was echoed by Keshram*. While discussing the reasons for his choice *he said that* ***the possibility of getting correct diagnosis and rational treatment is high at the government hospitals.*** This criterion plays an important role in serious and complicated conditions and to some extent for all other ailments that are not common routine illnesses and might require high cost of care. Treatment for such conditions was often obtained from government hospitals. However, for routine and common **illnesses it was assumed that advanced skills were not required neither for diagnosis, nor for treatment, hence, private clinics offering convenient services could be chosen since they provided immediate access to care with high end medicines, that gave quick relief and**

reduced the indirect costs of care. In some serious conditions that needed more skilled/specialized care and if there was enough experience in the community about similar conditions having been treated successfully in private hospitals, then economically well-to-do families used private care for an important / significant family member e.g. the head of the family, an earning member, male child etc.

The choice of government-run health institutions was shaped by considerations and that varied by levels of care. Given that the study village was a village with PHC, many respondents had used it as the first point of seeking care since it was most **the conveniently located and** the respondents could just walk in there. However, the use of block-level RH and district hospital with medical college was shaped by various factors such as emergency condition, accidents, injuries, medico-legal case, seriousness of illness with anticipated cost of care, and patient affordability. *She (Ujala) said that while she was sleeping in her house, a stone kept on the tin roof fell on her head, w**ith this significant head injury she became unconscious. She was immediately taken to RH Kandahar, where the doctor referred her to the government medical college and hospital at Nanded where she was taken in a private rented vehicle on urgent basis**. She was admitted in government the hospital and the initial treatment with injectable medicines and IV fluids was started. She was investigated for many blood and radiological tests. The hospital conducted a CT scan of her brain. Ujala was admitted in the hospital for five days and finally discharged on fifth day.* The choice of the government hospital could have been due to many factors- the timings- it was late night, an accident that could possibly have been treated as a medico-legal case, and the doctor at RH Kandhar had referred them to Nanded, specifically mentioning the government district hospital. Ujala was unconscious and in a very serious condition, which further complicated the situation. Given this **possibility of medico-legal case,** potential complications and **severity of the condition, a private hospital might not have admitted her so the only option left was that of a government hospital.** Even if had been admitted in a private hospital, the cost of care would have been prohibitive, which they could not have afforded. In the light of all these considerations, she was admitted to the government hospital. Thus **assured care for a serious condition and the likelihood of acceptance even in the event of a medico-legal case** is what defined their choice of care provider in this instance.

In case of accidents, injuries and emergency conditions, rural communities usually chose government hospitals. This choice has many determinants as discussed above. Government hospitals, especially the **RH is usually the only hospital at block level providing 24*7 services with availability of doctors and other support services like laboratory and ambulance service.** However, the private specialty hospitals that had emerged in the block town, were also acting as points of care for emergency health conditions especially if the doctor's specialization was suitable for treating the health condition. *Asaya had snake bite late in night, her family members identified the snake as a poisonous one and decided to go to Mukhed (the adjacent block town- at almost same distance as Kandhar town), to Dr. Shende. Madhukar, Asaya's husband told her that* ***Dr. Shende, was famous and very well-known doctor for treating snake bites in that area****. She was taken to Mukhed to Dr. Shende's private hospital in an auto rickshaw, for consultation and taking treatment. When they reached the private hospital,* ***they found out that Dr. Shende wason leave, which left them with no option but go to RH Mukhed.***

Some community members preferred treatment from other systems of medicine especially Ayurveda and had chosen their health care provider and hospital based on this preference. There was a widespread assumption that Ayurvedic treatment was free from side-effects. The choice of a particular system of medicine has its own history and determinants. Those who had experienced no relief or only partial relief from symptoms after visits to many GPs and specialist doctors in the district, chose to try out alternative systems of medicine. Nanded had a reputed government Ayurveda medical college and served the purpose of giving ayurvedic care to those who preferred it. It was known among community for its treatment of paralytic illnesses. *Teena Kore, had experienced little relief after having consulted and sought treatment from a few specialist doctors for facial paralysis. Vithoba Kore, her husband, then took Teena to the government ayurvedic medical college and hospital for treatment. The* ***decision to take her to ayurvedic hospital was based on the past experience, of a community member, for who ayurvedic treatment had been better for treating paralysis. According to the Kores, they had seen many of those referred to the ayurvedic hospital for the treatment of paralysis, especially those with affected limbs, had experienced improvement,*** *after different herbal and oil massages at the ayurvedic hospital* **.**

While people also chose alternative systems of medicine, it was ayurveda that predominated since there were many ayurvedic practitioners in the district and a functional Ayurveda medical college hospital. In addition to Ayurveda, some respondents had taken recourse to faith healers, especially for chronic illness, that were not responding to treatment by modern medicine.

3.1.3 Choice of private sector utilization

General Practitioners from block town Kandhar were the predominant private sector providers used for their routine health care needs. The convenient and effective services offered by the GPs were some of the important reasons for this preference of people. For most illnesses, unless considered serious or if the doctor was not available at PHC, the services of GPs were the second level of service that people considered after the PHC in their village. Therefore, in many cases there was experience of some care sought from PHC before going to GPs' clinics at Kandhar. Both PHC and GPs were usually sought for routine illness and minor healthcare needs.

After the option of PHC was exhausted, the choice of health care provider sometimes was made based on the **likelihood of getting their preferred form of treatment**. The preference was usually in the form of injectable medicines and IV fluids, the underlying assumption being that injectable medicines were more effective and IV fluids more energizing and effective in restoring health. This preference usually exercised for small, routine illnesses. *Many of the respondents said that the preference for* ***private clinics was partly because they administered injections and IV fluids on request. The respondents considered injections a better form of treatment than tablets. One of the*** *reasons for bypassing the PHC was that PHC doctors did not give injections and IV fluids often. If the treatment at PHC did not give them the desired results, the GPs were the next option. GPs catered to their demand of injectable medicines.*

People tended to believe that **prompt treatment with high end (‘*Bhari’ a Marathi term used which implies various meanings such as latest generation, higher dosage, better quality and expensive)*medicines reduced the total duration of illness. It also cut down much of the indirect costs as it reduced total cost on traveling, repeated visits and trying out different sets of medicines**. Also, it reduced the total duration of illness as one got cured in a short time and experienced faster relief with better medicines. It also meant avoiding or minimizing wage loss due to ill-health. Chances of getting prompt treatment with high-end medicines were higher

at the private hospital. Thus, often the indirect costs of seeking care at private clinics for conditions not needing admission, may be lower. This prompt and intensive treatment at private clinics was one of the important reasons for choosing them over government health centres, despite their relatively high consultation fee as compared to the free services or nominal charges at public health care institutions.

Along with the above-mentioned factor of preferred and effective treatment options in the private sector providers in the private sector were also chosen because of the likelihood of getting treatment in a satisfactory and dignified manner. The issue of **appropriate behaviour by doctors and other hospital staff with patients and their attendants was significant in shaping the choice of care providers especially if illness was not considered very serious. The appropriate behaviour that people expected** *started with spending enough time to examine the patient and take their history properly. The doctor must understand the patient's concerns and the whole treatment process should be one where the patients are provided with information about the nature of their illness and possible treatment options. The doctor and other hospital staff should behave in a humane, polite and dignified manner with the patient and their attendants. Most of the time the experience of receiving treatment was almost like adding insult to injury.*

Limited treatment options due to unavailability of doctors, health centres and hospitals got compounded further by **limited treatment options provided by qualified health care professionals**. Health care professionals sometimes did not attend even to the basic/ regular emergencies were also not addressed by for various reasons. Even routine health conditions for which a qualified doctor was trained were not catered to by the doctors in government hospitals, or even in the private sector, and **patients were referred** to higher levels. Many community members pointed this issue, commenting on nature of health services especially referral services, gave examples of pregnant women in labour who had been advised caesarean sections by doctors at the PHC, the RH as well as private practitioners, finally having normal deliveries, to give birth to babies en-route, in vehicles they were being transported, like auto-rickshaws and jeeps. These, necessary or unnecessary, referrals are one of the important reasons affecting the choice of health care providers. Such unnecessary referrals, spoke volumes about the quality of health care available, also discussed further in the section on referral services. The advice of referral is

usually done in terms of town or level of health care and without specifying doctors or health centre or hospital. The choice of the provider for seeking advanced care after referral was also governed by many factors including the specialty of the doctor/hospital in dealing with illness, the cost of care, past experience, convenience in seeking care and follow up. *After observing Sulekha in labor pain, the private practitioner said that she had lost all the amniotic fluid (fluid around the baby). He advised them to go to either Nanded or Ahamedpur. This advice from the doctor, conveyed to them the seriousness of the condition and they decided to leave quickly. They doubted the ability of the PHC set up with the just a sister available there, to handle the serious condition that Sulekha was in and avoided wasting time by visiting the PHC. Sulekha's father-in-law was of the opinion to take her to Nanded at SGGSMC and District hospital. He had previously had favourable experiences at the district hospital since he had taken both of his daughters for deliveries there. However, Sulekha's parents insisted on taking her to Ahamedpur, at greater proximity to their home, which would have made it easier for them to take Sulekha home post-delivery. Had she been taken to Nanded then her in-laws might have been taken her there since it was closer to them and Sulekha's parents insisted on taking her to Ahamedpur. As was the custom,* ***delivery and other costs, in addition to the post-natal care were the responsibilities of the girl's parents.*** *Hence everyone agreed on Sulekha's parents' convenience when they chose to go to Aahmedpur.* Thus secondary level care was chosen on the basis of social and economic considerations, physical distance, logistics and convenience. Therefore, it became evident that as the level of health care changed, concerns and expectations about quality changed. **Convenience, ease of follow-up visits, the ability to mobilize resources and help along with ability to get materials like food and clothing from home were important concerns for people. This made distance of the health facility from their households** also an important concern of quality

Refusal of treatment and referral to a higher centre (even for simple and routine illness) especially from lower levels of health care like the PHC was repeatedly pointed out by community members as the reason for seeking care from private GPs at block town of Kandhar. These GPs are single-doctor-one-room clinics that gave treatment and relieved suffering of the patients referred by the medical officer of PHC who was usually the more qualified and experienced and better endowed with infrastructural facilities of PHC. Limited availability of different medicines in the PHC and the PHC village as compared to block town could only

partially explain his refusal/ avoidance of treatment and the frequent referrals. *Krish, had developed fever and cough. His mother took him to the PHC from where she was turned away without any treatment, being told that she and her child had low levels of blood and it was a serious issue. Soon in a day or two, the condition of the baby worsened, with symptoms like abdominal breathing with high grade fever and cough. The mother sought her sister's help to take the baby to Kandhar. In Kandhar,* ***she visited the private clinic of Dr. Gudewar a BHMS doctor who*** *was chosen because of the family's familiarity with him since he had been visiting Panshevadi village for the past 2-3 years as a private practitioner.* Some **familiarity, social connection and rapport with health care provider are important concerns of quality** for people.

Persistence of symptoms despite completing treatment and follow up was a logical reason as far as respondents were concerned when they resorted to a different health care provider or institution, usually chosen for their higher level of expertise and/or qualification. *With little improvement in the baby's condition after seeking care from two private doctors in Kandhar, they decided to take the baby Krish to Nanded. Here t****he baby was shown to Dr. Balikar,a child specialist who was chosen following the advice of a relative from the Panshevadi, who was present in Nanded****, to attend to his son admitted in another private hospital. Sumangal's son who was 4 years old then, had developed cough with expectoration three-years earlier. He was taken to the PHC a couple of times but there was no improvement. He was then taken to Dr. Gudewar a couple of times which also did not help. Later he was taken to Nanded to a paediatrician, where the baby got better. was investigated- he had chest X-rays done and the mother was told that one of the wind pipes had become narrowed. When asked why they did not take the baby to the RH instead of the private clinic of Dr Gudewar, the mother replied that* ***since the baby didn't show any improvement after treatment from the PHC, it meant that the illness was serious. Thus she believed that it would not be possible for similar government doctors at RH Kandahar to manage this serious illness with similar set of government medicines.*** *She* ***admitted that she did not consider the qualification of the doctor in terms of whether they were MBBS or BAMS or BHMS*** *at Kandhar (in practical terms these qualifications didn't matter as it was observed that all these GPs with degrees from different systems of medicine were practicing only modern allopathic medicine) and that was evident from their choice of the* ***known and familiar BHMS Dr. Gudewar over the relatively unknown***

MBBS doctors at RH. *However, when treatment from their regular GP in the block town failed, they chose a paediatrician at Nanded.* Thus, RH Kandhar was avoided or bypassed since as it was considered similar to PHC in terms of the ability of the doctors and medicines provided. It was believed that if disease could not be treated at the PHC then it was less likely to be manageable at RH Kandhar.

For minor and routine illnesses, **quick access to care and early relief from symptoms along with some basic human decency** was preferred while making the choice of healthcare provider irrespective of the provider's qualification and expertise. *When the question of the better qualification and greater experience of government doctors as compared to most private doctors including Dr. Gudewar with a BHMS degree was raised, he (krish's uncle)said that while they had more degrees and might know better treatment options, they did not treat patients in time, or in a dignified manner. There was no willingness in government doctors, though highly educated, to treat patients. Many a time they neglected the patients or relegate their treatment responsibilities to the sister or compounder. Thus, he pointed out once more that the* ***health workers' attitude and behaviour were important factors affecting the treatment experience****. He said that the qualification of doctor is considered only in case of serious illness. "If it is just diarrhoea, then there is no need to see whether the doctor is MBBS or BAMS."*

For some community members, the complexity of qualification, expertise, and medical professional specializations were too difficult to decipher. The experience of fellow community members with similar illnesses acted as sufficient ground to seek health care from the same provider for those who did not understand specialty and specialization. Ujala suffered from burning micturition for years and experienced failed treatments and partial or temporary relief during treatment from most GPs in Kandhar and from Medical Officer of the PHC. Later she *(Ujala) and husband decided to go to Nanded to get treatment. T****hey had heard from some community members and relatives in the village about one of the Private nursing homes in Nanded run by Dr. Trishila Padam****. Some women from the village had gone to this nursing home for deliveries and hysterectomies. This was one* ***nursing home and gynaecologist they were aware of through the community members.*** This knowledge of Dr. Trishila Padam as a doctor providing services for women's health problems was used by Ujala to visit her for a consultation.

The community experience of government-run health institutions was a mixed bag. Having a good or bad experience at government run health institutions was affected by many factors some of which are discussed in subsequent sections. One reason that emerged in multiple interactions with community members was that the possibility of getting better and quick care was there in government hospitals if one knew the doctors or hospital staff personally. In government hospitals, when there is a relative or acquaintance in the hospital staff, the likelihood of **getting through the bureaucratic process quickly and getting better treatment** is high. Hence having such a connection was one of the factors affecting the choice of health care institutions. *Ujalawas visiting private clinics in the same town; sometimes she would walk down the road where the RH was, even walk past its gates to the private clinics further down get treatment from them, but had not been to the government RH. She said that if she did not experience relief after trying so many private practitioners, there was no possibility of her getting better at a government hospital, implying that the government hospital was incapable of treating her condition. On probing whether this belief had something to do with her perception that the seriousness of her condition may be beyond a government hospital's capacities to treat, she explained that one needed familiarity or connection, with the hospital staff; or political connections, significant clout or the ability to influence, then it was possible to get better treatment at government hospitals.*

Previous experience with a health care provider or hospital affected community members' decisions pertaining to care seeking. To some these experiences were significant because they **were anchored in interpersonal interactions, or some of these related to facilities and amenities at the institution, and to yet others the relief they experienced in their previous interaction with the provider was what counted.** People might sometimes club these different aspects and apply their assessment to all institutions similar to the one they approached. Sometimes experiences were analysed and remembered by people in terms of human expertise, or the materials and consumables used in those institutions. The referral linkage in these institutions and comparability of the institutions is also considered while making decision about care provider and institution. In case medicines of one government health centre were not providing relief, the assumption might be that the same set of medicines might be used in other related government health centres/hospitals. *They assume that if the ailment does not respond to the medicines provided at the government-run PHC then it was less likely to respond to the*

medicines provided at the government institution RH at Kandhar, so they went to a private clinic directly.

Nayan and Ranpatp referred a private clinic at Kandhar over the government RH. This was based on their past experiences when the doctors at RH Kandhar had shouted at them for approaching the RH instead of the PHC at Panshevadi. According to the doctors, the same ailment should have been tackled at the PHC. Doctors at the RH had told them that PHC was equivalent to RH Kandhar, and in many aspects like medicines and facilities, as compared to the RH. ***They had been sent back often, without any treatment from the RH. The RH would offer treatment only for*** medico-legal cases and some emergencies like snake bite, accident, injury, delivery etc. The **unfair scolding from doctors had resulted in them avoiding RH.** These responses from the doctors at the RH raised their expectations from the PHC and led to an unnecessary comparison of PHC with the RH, blaming the PHC for being inefficient, unsatisfactory and having a limited range of medicines and services. It was also possible that simple health conditions were being referred by the doctor at the PHC for the lack of medicine or diagnostic facilities or a lack of skills or simply to avoid work. In these dynamics, patient suffers and is pushed in to private sector.

Many respondents articulated refusal of care or incomplete care, **lack of relief from symptoms or partial relief from symptoms and suffering** as a constant theme and an important reason for changing the health care provider. *After trying out treatment (and experiencing no relief from the symptoms) at PHC Mayabai's family had shown her to a few private practitioners in Kandhar, that was the nearest town. Private practitioners consulted included Dr. Gudwane a BAMS doctor (a well-known private practitioner), DR. Ghardivea MBBS doctor (also a well-known private practitioner with a hospital of his own) and Dr. Khure MBBS, DGO(private specialty hospital of Gyn/obs). All of these doctors gave Mayabai injectable medicines during out-patient visits and some oral medicines to be taken for 10-15 days. She had completed the course of medicines prescribed by all the doctors, but did not have complete respite from her symptoms. On an average, they had to spend Rs. 200-500 at every visit for the treatment at Kandhar. Therefore, it did not make any sense (since there were no benefits despite completing treatment and spending money and time) to continue the treatment in similar set ups.*

Persistence of illness and suffering despite treatment raised doubts about the ability of the provider. If multiple providers failed to ensure desired results or relief from suffering then the both the **level of health care provisioning and level of expertise were considered inadequate, requiring the users to move to another level** of health care, where the expertise was more advanced. *Bishan (Mayabai's husband) said that the doctors in the private **hospital and clinics** with similar experience and expertise could not cure her condition, it was less likely that RH Kandhar could have helped any better. With overall experience, he thought that the doctors (from the private sector) in Kandhar did what they could in their capacity, and her condition was serious and needed treatment at a higher level.*

The higher level of care may be in the form of expert opinion, advanced diagnostic facilities or intervention facilities for illness. *After trying out some of the good doctors in Kandhar Bishan and his family decided to take Mayabai to Nanded for further treatment, making use of diagnostic technologies like USG, following the advice of one of his friends who suggested that 'if she is having pain in abdomen then she might need a USG examination'***.** *In Nanded they visited Dr. Bawadekar's Hospital, a multi-specialty hospital with specialists in surgery, gynaecology, paediatrics and medicine.*

Sometimes, **fame and expertise of a doctor/health care provider** acted as a magnet attracting patients. The reputation and shared faith in an expert made the expert a reference point. The consultation and opinion from this expert usually put an end to many speculations and doubts over illness, its possible consequences, and effectiveness of ongoing treatment as well as on the sincerity shown by family members in care for the person with illness. This expert opinion gave people the satisfaction that they had done their best to care for the person with the illness. *Asaya was treated for a poisonous snake bite at the district hospital for five days after the initial treatment and referral from CHC Mukhed. Her life was saved at government medical college hospital. Four days after the discharge (from government medical college hospital) the fluid started appearing and accumulating in the affected skin over her ankle joint. Over the next few days the area became a little soft, with a few blisters filled with fluid. Neighbours, relatives and well-wishers who visited her check on her health after the life-threatening venomous bite conjectured that there was chance that some poison must still be left in the body and would affect her after the effect of the medicines given waned off. The comments from neighbours and*

relatives coupled with the changed appearance and fluid accumulation at the site of injury, made them to ***decide to visit Dr. Shende, a doctor well-known for treating snake bites. They had previously tried to get treatment from him but he was unavailable at that time. They thought his opinion would be of great help, having heard from some people, who had been to Dr. Shende's hospital, that it had different kinds of snakes stored in glass jars. If one identified the type of snake which had bit them then he offered quick and effective relief. This paraphernalia of specimens of local snakes was impressive to many people including Madhukar and had added to the doctor's fame.***

The fame and popularity of a doctor was not always for his/her qualification and expert skill sets and experience of giving technologically advanced care, sometimes it was for their **sensitive nature, sincerity and earnestness in taking care of patients and advising treatment. If the health care providers showed empathy to patients and were aware of patients' context while advising the patient, this sensitivity and good nature of doctor also earned him good repute and served as an attractive feature for the patient**. Shambhu *stayed in Panshevadi with his paraplegia for two days waiting, mobilizing funds for the further treatment. Since there were no superficial injuries he had not realized the seriousness of the ailment. He was then taken to a private hospital in the district headquarter town. He had* ***chosen the private hospital due to one of the doctors there, Dr. Pagare (****an M.S. in general surgery****)- who had earlier been working as the Medical Officer at the Kandhar CHC/ RH.* *Dr. Pagare had worked in the CHC/RH for a significant period of time and was quite* ***well known in the entire block, for his good nature.*** *Shambhu was admitted in the Aksha Hospital (a medium sized (bed strength about 30) multi-specialty hospital run by group of doctors) under Dr. Pagare. Some of the doctors including Dr. Pagare were earlier fulltime medical officers in district of Nanded.*

The **familiarity with the health care provider** played an important role in their selection. Past experience with a health care provider led to some familiarity and rapport with a doctor. This experience was useful in the subsequent decision to seek care from the doctor. However, when such familiarity was absent or such an option was unavailable, then other social factors like language, religion, region, caste, gender etc. of health care provider also shaped, to some extent, the choice of the health care provider. These factors were considered means of invoking sympathy/empathy, diligence, and sincerity from the healthcare provider. *Sulekha's family*

reached Ahamedpur early morning at around 4-5 a.m. They went to a small private,6-8 bedded hospital, called Padam hospital, also run by Dr. Padam MD (general medicine) and his wife Dr. Mrs. Padam who was an obstetrician (MD obs/gyn). ***The doctor belonged to the same caste as Sulekha's family, and they shared a distant link with him, given that one of their relatives was from the same village as the doctor.*** *This link and social relatedness were thought of as a possible avenue to seek some concession in the total hospitalization cost, and it was thought the link would fetch them attention and good care. They believed that Dr. Padam was a medical officer of the CHC Ahamedpur and were doubtful of finding him early morning at the CHC. So, they decided to take her to his private hospital where he would have been present. Thus, in addition,* ***immediate availability of doctor for patient care, the chances of getting preferential care*** *from private hospital made them choose his private clinic, especially given the odd timing.*

Sometimes, there is difference between choice of health care provider and care/ treatment from the provider. Many a time, a famous or highly specialized doctor or hospital was chosen for an opinion on a health condition, the treatment and advice offered by these providers and hospitals were used depending on various factors. **Affordability of that care** was the most important factor, especially for surgical interventions or advanced non-surgical interventions requiring hospitalization. Private hospitals were expensive compared to government hospitals, especially for care requiring hospitalization and surgical interventions. There was also a growing doubt about the necessity of the interventions advised and hospitalization suggested by private sector hospitals. Even if the consultation and advice were sought from these doctors, respondents did not always choose to follow everything they advised. The decisions, especially around care requiring hospitalization and surgical interventions, were governed by many factors and were not necessarily as recommended by the doctor/ hospital who had advised for it. *Sulekha's family requested the Dr.Padam to inform them about his decision (whether she would need C-section or it will be a normal delivery) by 10 pm, so that they could arrange for their transport to the Nanded district hospital. Arranging a vehicle after 10.00pm was difficult. The doctor examined the patient again and promised them a normal delivery. After midnight, at around 12.30 to 1.00 am, the doctor said that she required an operation and they were asked to choose between getting her operated there in the hospital or shifting her to wherever else they preferred.* ***That late in the night they had no option but to get operated there, since no private vehicles were***

available in a new town for them to shift the patient. They chose the care from the same provider even though they had option of going to the government medical college hospital.

Many a time in the face of a health condition that demanded immediate attention and care from the specialist people had little choice. **Either the available options were too few or there were none or just the one**. *When the family was told about the meconium aspiration pneumonia and condition of the baby (during her second delivery), they attributed it to the actions (acts of commission) of Dr. Khure (obstetrician from adjacent hospital) who was invited by Dr. Yadav(obstetrician) to assist him in Caesarean section. Dr. Yadav's subsequent advice about getting the baby admitted at Dr. Mrs. Deepa Khure's (Paediatrician) hospital was not acceptable to Sulekha's father in-law- Nayan and his family. He refused to get the baby admitted in Dr. Khure's Hospital. However, there was no other option that late in the night (around 10 pm) but to admit the baby there instead of shifting it to some other town. Dr. Yadav and all of Nayan's relatives requested him to get the baby admitted at least for that night in Dr. Khure's hospital. He agreed to it and sent the baby, the relatives and Sulekha's father to Dr.Khure's Hospital.* Nayan had a bad experience previously with Dr. Khure; his niece's new-born child had died while being treated at his hospital. Despite this bad experience he agreed to admit his new-born grand-child at Dr. Khure's hospital due to lack of options at that hour and given the baby's health condition.

Community members also chose care in a private hospital at times owing to **social pressure to maintain their social prestige. If they took their family members, specifically old parents to government hospital then there were chances that it would be read as reluctance to take care of them and he would be taunted in his social circles for the same, for his refusal to spend on his parents trying to save money etc.** There was **also social pressure to seek obtain treatment specifically at a better place like Kandhar town or higher up at district level, as was evident from some other interviews and discussions among people in the village. Treatment sought from the big private hospitals reflected or was read as a person caring for his family members (especially to old parents) and did not mind spending some money for it.** These notions were developing in the backdrop of deteriorating quality in government-run health services, and deterioration in the content and behaviour of health workers. Treatment at

the government hospital, it was assumed necessarily came with some inconvenience, inappropriate behaviour which at times could even be dehumanizing.

In one of the above sections, it was discussed that the choice of healthcare provider' did not necessarily mean opting for all treatment available from that care provider or institution. Sometimes after the expert opinion was sought, the decision to take treatment - especially surgical interventions or other interventions requiring hospitalization were shaped by various factors. One of those was considerations of the **continuity of care**, the explanation of nature of illness, prognosis and line management advised, and most importantly, **assurance offered in treating the illness**. If the prognosis and line of management did not have intended or desirable outcomes, then the health care provider was changed. *When Asaya and Madhukar came outside after consulting the famous snake bite expert, Dr. Shende, some people outside the OPD had asked them how the doctor's consultation and advice had been. Madhukar told them about the consultation and advise which consisted of an operation costing him at least Rs 25,000. Some of them told them to go and visit a traditional healer in the nearby village who was very well-known in that area for his treatment of snakebite. They told him that he offered* ***free treatment****. They further said that it had been a very* ***effective treatment*** *as some of them had seen patients recovering from serious snake bites and snake bite wounds larger than what she had. They added that some patient who had even been advised operation had gotten better there. They added that a patient who had been advised amputation of leg, and was scheduled for operation in a few days got better with the Ayurvedic treatment given by that person. They said that many patients would seek treatment from the herbalist, after consulting Dr. Shende. They had gotten better. Madhukar, further added that choice of the herbalist was based on the reason that* ***his trajectory and line of treatment did not have amputation in it****, though it was a longer treatment. So, the chance of her becoming physically handicapped and a liability was less, with the only inconvenience being the longer duration of treatment. Whereas the modern system of medicine, as experienced at Dr. Shende's hospital and seen in one of the known person's case, consisted of set of operation and amputation as one of the last measure in the line of treatment suggested.* ***So, they chose a line of treatment and trajectory which did not have the option and measure of amputation and making her handicap. They said that they also believed in the Ayurvedic form of treatment.*** *However, they were still open to the option of going back to the government*

hospital for further treatment if the herbal treatment did not yield the result in the time frame given by the herbalist practitioner.

3.1.4 Summary

Table 3.1 Desirable and Un-Desirable Aspects of Experience and Expectation from Health Services Based on Choice of Providers

Desirable aspects of experience and expectation from health services	Un-desirable aspects of experience and expectation from health services
<u>System structure of health services</u> **Nearest health care provider- especially if its emergency or accident – distance and proximity** • physical distance, logistics and convenience it offers in access. • possibility of addressing medico-legal concerns • convenience in seeking care and follow up.	• lack of options
<u>Attributes and features of provider</u> • specialty of the doctor/hospital in dealing with illness, • social factors like language, religion, region, caste, gender etc. of health care provider also shape, to some extent, the choice of the health care provider. These factors are considered mediums of invoking sympathy/empathy, diligence, and earnestness from the healthcare provider. • Reputation based on past experience- • familiarity and rapport with a doctor • ***sensitivity in approach to suffering of the patient*** • appropriate behaviour by the hospital staff • ***known and familiar provider*** • care provider's qualification and expertise- in case of serious illness • *health workers' attitude and behaviour* ***as an important criteria affecting treatment experience.*** • expert opinion from a **famous doctor** gives satisfaction that one has done best possible effort to care for the illness • sensitive nature, sincerity and earnestness in taking care of patients and advising treatment. If the health care providers show empathy to patients and is aware of patients' context while	

advising the patient, this sensitivity and good nature of doctor also earn him good repute	
Medical/ clinical care components • **Prompt treatment with high end medicines** • ***possibility of getting correct diagnosis and rational treatment – especially or chronic and serious conditions*** • quick access to care and early relief from symptoms along with some basic human decency was preferred • explanation of nature of illness, prognosis and line management advised, and most importantly, assurance offered in treating the illness.	• partial/incomplete care • non-relief from symptoms or partial relief from symptoms • limited treatment options provided by qualified health care professionals. The basic/ regular emergencies are also not addressed • Non relief from symptoms despite completing treatment
Institutional features • likelihood of getting treatment of choice • **getting personalized services**. • getting better and quick care • providing 24*7 services with availability of doctors and other support services like lab and ambulance service. • fame and expertise of a doctor/health care provider • preference of medicine system used for treating illness.	• Refusal of care/treatment and • referral to higher centre (perceived as unnecessary) or even something undesirable feature of institution/system
• financial constraint shape choice • cost of the care, past experience, and • Affordability • **social pressure to seek treatment from private** • **reduces total cost on traveling doing repeated visits trying out different sets of medicines.**	

3.2 Quality perceptions from overall experience of seeking care

After the discussion on factors affecting choice of health care providers and institutions it is important to understand actual experience of seeking care. Many a times, there is difference between expected/anticipated care and the experience of actual care received. This section discusses experience of care-seeking by people, as narrated by them without much probing about different aspects of health care delivery. This section covers broad experience of community members with different institutions and providers that they had used during the course of their care seeking journey. The chapter includes indicative experiences about interactions with health

care institutions at different levels in both the public and private sector. Subsequent chapters discuss this experience as elaborated upon by the respondents when the researcher probed them on the experience narrated and specific themes.

Discussion with community members on their experience of care seeking differed in two major ways. Some respondents anchored their narrative of experience in institutions like PHC, RH, medical college DH, private hospital or clinic, while others were centred on doctors and specialists. Therefore, these two have been discussed in separate sections to bring out different factors shaping perceptions of quality, cast light on factors relevant for quality in healthcare. This separation would be of relevance for policy interventions on quality as these would need different kinds and levels of interventions for assessing and improving quality.

3.2.1 Experience with different health care institutions (PHC, RH, DH, Medical college, GP, Private hospital, multi-specialty private hospitals)

Community members from Panshevadi were mostly seeking in-patient care and specialist OPD consultations at the private hospitals and the government hospital in Nanded. One major and consistent experience that was articulated in their experience of seeking care at Nanded was that of inconvenience that the long distance, of around 70 Km posed. The hospitalization facilities closest to the village was the RH at Kandhar, was 15 kms away while the other options for hospitalization were at Loha RH and Mukhed CHC at a distance of 25 Kms and 30 Kms respectively. Kandhar was closest and most convenient town with RH and private hospitalization facilities too- two private nursing homes run by gynaecologists, one of them also had a paediatrician too.

Rural Hospital

The respondents of the village did not report much use of RH Kandhar except for emergencies like snake bites, accidents, injuries or child birth. In most of these emergencies the RH Kandhar acted only as stopover from where the patients were usually referred to Nanded. The community members had used RH Kandhar occasionally and it did not appear significantly in their care seeking journey. Use of this level of RH/ CHC, when reported, was usually for child birthing services. Private GPs from Kandhar town were extensively and routinely used in their care-seeking for different ailments but RH Kandhar was hardly used despite having more qualified

doctors, indoor facilities, some basic investigation facility, and free medicines. RH Kandhar could not earn a place or may be is lost in community memory of being an institution providing routine curative services and hospitalization care, except for pregnancy and child birth. The reasons for this are many and have been explored to some extent in subsequent chapters. In some interviews respondents said that ***they assumed that if the ailment did not respond to the medicines provided at the government-run PHC, then it was less likely to respond to the medicines provided at the government institution at Kandhar as well since they believed*** **that the same medicines were possibly being supplied in these government-run institutions PHC and RH.** According to Nayan and Ranpat, **they thus preferred to go directly to private clinics** at Kandhar over the government RH. *In the past on many occasions, doctors at the RH Kandhar when realized that the patient was from Panshevadi, a PHC village, would shout at them asking the reason for their visit the RH since the same ailment could, and should have been tackled at the PHC. They were often told by RH doctors that the PHC was equivalent to the RH Kandhar, and in fact had better medicines and facilities as compared to the RH. They had been sent back* ***without any treatment from the RH several times, with the instruction to get treated at the PHC. However,*** they did attend got treatment at RH regularly for all medico-legal cases and some emergencies like snake bites, accidents, injuries, deliveries etc.]. Hence **the scolding and humiliation at the hands of the doctors at the RH had caused them to avoid the RH.** These responses from the doctors at the RH also had the effect of raising their expectations of the PHC and led to unnecessary comparison of the PHC with the RH, blaming the PHC for inefficient, unsatisfactory and limited range of medicines and services.

However, when it came to services related to pregnancy and child birth, the RH managed to provide some care services. *Kavita's example was a case in point. When labour pains started Kavita was taken to private nursing home in Loha (a block town 15 km away from Kandhar). She was in Loha at her parents' house for deliver. After examining her, the doctor from the private nursing home said that she would need 2-3 days for delivery, hence the family decided to take her back home to avoid hospitalization costs. On the same day, a little later, the doctor told them that by 8 in the night the baby would be delivered. Contradictory opinions from the same doctor caused them to be doubtful and Kavita and her family anticipated that the doctor was possibly planning for a caesarean section operation. In order to avoid possible surgical delivery, she was taken back home. When labour pain resumed the next day she was taken to the RH, because*

getting admitted in a private hospital for 2-3 days would have been costly and there was also the possibility of the caesarean operation in the private hospital. The ***medical officer on duty, Dr. Gavade, examined and admitted her, which was followed by an examination by the CMO Dr. Panwate who said that it would take two days. Kavita and her family were offered both options of staying admitted or going back home to choose from. They opted to stay admitted, and found the hospital staff, the sisters helpful and spoke nicely to her. She found the hospital premises, delivery room, and ward appropriate and well maintained. Kavita felt that her overall experience of getting delivered at the CHC had been good.***

Immediately after delivery, the baby was handed to the mother for breast feeding, she and baby were given some injections and the baby was also given oral polio drops. The family members had been asked to obtain from outside a few injections at the time of delivery. The medicines that were bought by the family members were given to Kavita immediately after delivery. She was discharged from the hospital on the same day of delivery. The ***doctor present in the hospital at the time of delivery had examined her once before delivery, and had given her the anaesthetic injection for episiotomy which she eventually did not need.*** *Kavita's uncle was a friend of Dr. Panwate, the chief medical officer. This familiarity may have contributed to her good experience in the RH Loha.* Except for child birthing services experiences of hospitalization at the RH were not reported in a positive light. For most other serious and emergency cases the RH served merely as a stopover that provided some immediate care and referral to other institutions.

Primary Health Centre (PHC)

The PHC's location in Panshevadi offered some advantage in using its services. Individual doctors at the PHC had significant place in the narratives of the experience of health care at the PHC. The medical officer -Dr. Gedam or earlier other doctors like Dr. Butte etc; and Gavade sister- the ANM who lived in the PHC were the healthcare providers often mentioned by respondents. While some of these experiences as were anchored in individual providers at the PHC, most of the experiences of care were for minor illness and pertained to the initial stage of their care seeking journey. The PHC managed to act as an institution of some use for their minor and routine health requirements during its morning working hours when the doctor was present. Experiences reported of the PHC also constituted a mixed bag and raised doubts of some preferential care for powerful people from the village. Some of these experiences have been

discussed in subsequent chapters. The PHC served as a dependable institution to provide ANC check-ups for pregnant mothers, *Sulekha got pregnant after 2 years of marriage.* ***Gavade sister at the PHC diagnosed her pregnancy****. Her* ***name was registered*** *and her* ***check-up included measuring her weight, height and abdominal examination.*** *Her* ***blood was also tested*** *once and she was told that report was good.* ***She was given two packets of (probably FS-FA) 30 tablets each to eat during her pregnancy that she*** *consumed regularly. Commenting on overall experience with PHC services for ANC care Sulekha and her father-in-law said that they were happy with the services provided. Recollecting his wifes operation at PHC Kurula Sulekha's father in law recollected that it had "****one good sister (nurse), Adhav sister"****.*

Other curative services provided by the PHC were very few and basic, indicated under-utilization of available material and human resources, and also suggested that there was much scope for improvement. The PHC services were contingent on the availability of drugs, medicine and other consumables, the availability of doctor in the PHC, skills, sincerity and earnestness of the doctor there. *Four months prior to this study one year old Krish developed fever and cough. His mother took him to the* ***PHC. As usual the doctor was absent and he was seen by the sister who was then present. After observing and examining the baby she said to the mother that the baby was serious and there was hardly anything that she could do, advising her to take the baby to Kandhar****. The mother said* ***that as usual she did not treat her child. Her past experience at the PHC was no different. Whenever she had gone there the doctor was absent, and she or her children (all three) were seen by the sister present there. On several occasions sister had suggested that she and her kids lacked blood in their bodies because of which she could not treat them and they needed to go to Kandhar for the treatment.*** Thus, the absence of the doctor, or lack of competencies and material support for treating the ailment was not acknowledged. It was ironic that an ailment was being used as an excuse to leave another problem untreated, possibly resulting in advancing the illness and pushing them to approach a healthcare institution at a higher level.

Cumbersome procedures to access care in Public institutions

The reasons and decision to choose or opt for service by a particular provider or institution didn't necessarily mean one would get those services. The narratives of community members revealed that it was not always easy to secure access to the health care provider or hospital that they opted

for or considered desirable. Accessing government hospitals, especially secondary and tertiary hospitals was a challenging task. The timings and limited number of OPD registration papers released in a day made it difficult to get an OPD paper and become patient of that provider or hospital. There was always a sizeable number of people with some illness or the other queuing to seek care at a hospital but unable to avail its services since they couldn't get the OPD papers. The restricted timings of the OPD were already challenging but the people traveling far distances from distant villages and towns, with limited public transport facilities had even greater impediments to battle to be able to consult a hospital regularly.

District Hospital

All those who were lucky to get an OPD paper might not be lucky enough to get in-patient care due to lack of beds or for not having an ailment of interest to the health care provider. *Shambhu along with his wife went to SGSMC and the district hospital, referred by the medical officer at the PHC for treatment of his bed sores (foul smelling – possibly infested with maggots). He spent almost an entire day in the hospital going through prescribed diagnostic tests -X-ray and USG of the abdomen. (one wonders why these diagnostic tests were advised for patient seeking care for bed sore on buttocks). In the late evening he was given tablets, syrup for relieving constipation, and some cream for application on the ulcers.* ***When he inquired about the possibility and need of getting the affected area dressed, they told him to wash his wound and apply the cream at home (an indirect refusal of treatment, incomplete treatment, especially the effort-intensive aspect of the treatment.) Handing over of prescription is not treatment for a patient having a bed sore, ulcer or sinus****. He was asked* ***to leave the hospital in the night and it was after much*** *requesting and* ***pleading with the hospital staff, to let him to stay since it was too late to find transport to travel back to his village and*** *he could not afford a privately rented vehicle. Though he was allowed to stay, the hospital functionaries asked him leave the hospital premises before dawn, after which he went to an Ayurvedic hospital in the morning, which he found shut that day. He approached the emergency department in the Ayurvedic hospital and was told that* ***he would need dressing, some injections and medicines, which could not be given from the Ayurvedic hospital, though it was*** known to perform surgeries and practice selective allopathic medicine, despite which they refused him treatment. *They referred him back to the SGSMC and district hospital, that had just refused him dressing for his wound. With nowhere to go, he spent the whole day on the street with his wife, resulting in the worsening of the wound which with had*

*developed one more opening on the buttock and had foul-smelling purulent discharge. W**ith none of the government hospitals showing any sensitivity to his suffering** and after spending a day on the street, he was left with no option but to resort to a private hospital. Due to his limited means he opted for a trust hospital which ran on a no-profit-no-loss basis, Tayar hospital, where he was admitted for almost a month and given treatment.* The challenges of finding effective care in tertiary care institutions were insurmountable many a time and hence community members preferred the private sector since there was a possibility of getting some care as opposed to waiting for OPD cards and or not getting a bed in a government hospital. For many, on the other hand, the costs of care at the private hospital were prohibitive and did not allow them to seek care. This translated into no care for many, if they had illnesses requiring specialty care and that was not available in a government sector hospital in the entire district. This kind of exclusionist practice in health care institutions resulting in delayed care or no care was difficult to capture from those who are currently hospital patients. Relying only on narratives of patients for understanding perceptions of quality might have resulted in missing this element of quality in health care and was captured by basing this study on the community.

Seeking access as a regular patient in government hospitals was cumbersome, confusing, time and resource consuming and particularly arduous, for a person with illness. Navigating the maze of infrastructural space, bureaucratic processes, internal divisions and referrals, institutional processes, timings, and being at the receiving end of technical language from very busy, overworked and unfriendly doctors in short consultations in a faraway town was a challenging task for rural persons. *Keshram, a college student, and the son of government health department-ambulance driver, , had a swelling in his neck, that was like a nodule, measuring around half to one inch in diameter. The swelling though painless, was growing very slowly. Worried, that it could be cancerous or might grow out of proportion, he decided to consult a doctor. **He first visited Dr. Butte, the medical officer in the PHC at his own village, who after examining the swelling told him that there was little he could do about it. Advising him to go Nanded and get a FNAC (Fine needle aspiration cytology) investigation, and followed by treatment according to the results of the test.** After some time **Keshram went to the government medical college and hospital at Nanded, where he paid for the OPD consultation and got the papers. On reaching the assigned OPD around 11.30- 12.00, he however found that since it was Saturday, the doctors had all left early and he was asked to return on Monday. He returned to his village,***

and got back to the hospital *on Monday, queuing up early morning outside the OPD for his consultation.* ***He had been given the papers/card for the skin department where the doctors after examination, referred him to another OPD, most likely surgery.*** *The d****octor at the second OPD after examination advised him to get a test done and referred him to another department for testing. The department for testing gave him another date for the FNAC test, forcing him to*** *return to his village gain. He went for FNAC testing on the given date, and* ***was asked to collect the report on another date after he had given the sample.*** *He returned to his village yet again. On the given date, he collected the report and went to the same department where he was advised to get the test. This time* ***the doctor who had prescribed the test was not present and the doctor present at that time, went*** *through the results and said that* ***report was normal, indicated nothing worrisome and there was no need to remove the nodular swelling. He was advised to go back home since the test was normal. (Doctors had sent him back saying that the result was normal, but he had visited them for the swelling which was an abnormal growth in his neck.)*** *He went back home and to college and did not consult any one, waiting for the swelling to subside for almost six months. Not only did the swelling not subside; on the contrary there was a marginal increase in its size, posing a dilemma-* ***normal test results for, swelling that refused to subside.*** *The swelling in the visible regions of the neck of 20 year old could have been a concern about how it looks. Everyone in his family also advised him to consult the doctor again and get it removed. They feared that it would turn into a complication or a cancerous condition. After hearing the concerns voiced by his family members he decided to go again and consult a doctor. Keshram returned* ***to the government medical college and district hospital at Nanded. He went through the routine of waiting in queue for the OPD papers, then at the surgery OPD and he showed his swelling at to another new doctor. After examining the swelling and going through the previous reports doctor advised him to do the FNAC test again to see if there was any change. Following the same process, he managed to complete his FNAC test and get the report, returning*** *to the doctor in the same* ***OPD, this time to be seen by a lady doctor****. After going through the reports she said the him that the report was normal and suggesting nothing to worry about, asking him to back home without* ***worry, like the previous time.*** *He then asked the doctor what kind of swelling it was. Why was it not subsiding? When* ***he started inquiring about the swelling, its nature, and cause, the doctor asked him whether he wanted it removed. Keshram agreed for the removal of the swelling and was given a date in the following week***

and asked to come early in the morning after having breakfast. On operation day on enquiring further, the doctor told him that he did not need admission, so he waited in ***the queue outside the operation room waiting to be operated.*** *Doctors operated another person and then* ***called him in asking him to lie down on the bed. There was a tray on the table next to the bed where he was made lie. The tray had a mass of tissue smeared with blood and some surgical instruments. The bed sheet was bloodstained and Keshram found the place dirty and unhygienic. He was given an anaesthetic injection on the sides of the swelling, operated upon and the small nodular tissue removed. The wound was sutured and was swathed in a bandage.*** *He* ***was asked to wait for some time outside the operation room immediately after the surgery before the doctors prescribed him some oral medication****.* ***He left the operation room and waited outside the lift to go to the ground floor but the lift man refused to allow him to use the lift despite having been operated upon just then. Keshram felt very bad and insulted by the experience, resorting to the stairs.*** *He took the prescribed medicines and completed the treatment. His wound eventually healed completely and he was normal at the time of this study.* Keshram's care-seeking journey brought out how cumbersome and time-consuming it is for a rural person to take treatment from large institutions like medical colleges or District hospitals. The timings alone make it near impossible for many even to get the OPD paper! As a young man with no household responsibilities and very mild health condition Keshram could leave early morning reach the hospital in time; it would have been a challenging task especially for a woman with household responsibilities who would have to wind up her chores before she embarked on the journey to the district town. The repeated visits required for treatment at government hospitals make that care even more difficult to go through and add to the opportunity cost incurred. Keshram could get the required treatment because of his persistence and repeated visits, and willingness to demand for it with a firm attitude. His persistence and confidence in navigating institution of tertiary government hospital and its doctors could have been possible for Keshram as he was son of a government health employee, an ambulance driver, and was a graduation student of pharmacy. It was not a privilege available to most people using health care in a government hospital. The advantage his background offered and his persistence got him the required treatment from the hospital but he could not escape the insensitive institutional processes and hospital staff in the dirty and un-hygienically kept infrastructure of the hospital.

He was appreciative of the fact that he could get that operation at a very nominal cost; it could otherwise have been very expensive for him in a private hospital.

On the one hand is Keshram's long-winded journey of getting care, and on the other was the swift and earnest response of the same government medical college and district hospital and its chain of referral institutions like the CHC and PHC to a commonly encountered life threatening health emergency in the region- snake bites. Community, health professionals and health care institutions had, over a period of time, learned what needed to be done, their roles and responsibilities in the event of snake bites and knew how they were required to act in that emergency situation. *Asaya said that something bit her while she was sleeping on the ground and on hearing her voice, her husband woke up to find a long, thick, black coloured snake. The alarm and noise they raised caused their relatives to gather, who also* ***saw the snake, and examined her leg for the bite marks. The bite mark on her ankle*** *was a big penetration bite injury. Fortunately, the relatives with whom they were putting up had an auto-rickshaw of their own.* ***They tied a cloth band very tightly below her knee on the calf muscle in order to prevent the transfer of venom to rest of the body through blood circulation. She was taken the auto-rickshaw, to the nearest health center that was PHC Barul, 7 kms away. The medical officer at the PHC attended to her, and after taking the history and description of snake he gave her an injection and asked them to take her to sub-district-hospital (SDH) Mukhed or Kandhar, both of which were equidistant from Barul. The doctor gave them a referral slip****. The family took her to Mukhed, to Dr. Shende, in the same auto rickshaw. Madhukar, Asaya's husband, said that Dr. Shende, a physician, was very well-known for treating snake bites in that area. She was taken to Mukhed in the same auto rickshaw. They went to Dr. Shende's private hospital for consultation and taking treatment. When they reached the private hospital, they found that Dr. Shende was away at on a holiday. Hence, they were left with no option but go to the SDH Mukhed.*

RH Mukhed had been upgraded to sub-district hospital in recent past. The medical officer at SDH Mukhed ***examined her immediately, took history, and asked them for the description of the snake. After going through the referral paper, he gave her some injections- two each in the gluteus muscles on both side, and one injection each on both the deltoids. He then started her on IV fluid, with a few injections added to the bottle of IV fluid. It was realized later that the***

doctor had already called and asked for the ambulance to be ready. The band tied on her leg was released and after the injection, the doctor spoke to Asaya and noted her slurred speech*. He asked her husband whether the way she was speaking was normal, and he said that there was some alteration in her speech, increased slurring and a kind of stammering.* ***She then began to experience severe nausea and vomiting. The treating doctor observed that her condition was deteriorating and said that she would need hospitalization at a higher centre, at Nanded. He gave them a referral slip and asked them to go to Nanded government medical college and district hospital. The ambulance was made available and they were informed about the charge of Rs.800 fee they would have to pay for the ambulance.***

She was seen by the ***doctors at casualty in the government medical college and district hospital. After the referral slip (from SDH/CHC Mukhed) was read and the condition of the patient examined, she was admitted to the hospital and started on IV medicines and fluids from the hospital. Asaya was admitted there for four days. Her blood tests were done daily, her condition improved and her life was saved.*** *She was referred to the OPD no. 64, most probably surgery or the skin OPD.* ***The doctors in OPD 64 after observing her condition had prescribed her some oral medication. Doctors said that the swelling would subside with medicine, and the discoloured patch would resolve gradually. The doctor in OPD 64 had advised her to return for a follow up visit a week later, to assess her condition and for further treatment. On the day before discharge, her blood was tested three times.*** *She recollected that they used to test the blood also by pricking her fingers. (Possibly to check her bleeding and clotting times.) Doctors told them that her blood reports were normal and there was nothing to worry about the effect of the poison.* ***She was discharged from the hospital on the fourth day of her admission, with some more oral medication.*** This experience of care seeking was unusual and was contradictory to many of the experiences narrated by community members about government health institutions. Not all life-threatening emergencies received similar care and attention at government hospitals. The possible reason for such immediate attention and care provision could be because of reason the experience of health workers and doctors in tackling such emergencies, the availability of required material for managing the emergency. It was also important to note that most private hospitals did not treat snake bite cases (only exceptional private hospitals provided treatment for snake bites); anti-sera was available in government institutions and government hospitals are the major, often only source of treatment for snake

bites = This role as sole providers might have pushed them to be responsible in providing care. It was also possible that recent in-service training for the medical officers on snake-bites might have resulted in such a response. However, there was the community memory and experience of receiving prompt and appropriate care for most snake bite cases from PHC, RH and district hospitals.

Tertiary level health care institutions like district hospitals or medical college hospitals are institutions where bulk or majority of the medical/surgical interventions take place; difficult, serious and long-term diseases are cared for through a plethora of curative interventions. These institutions with different OPDs and large hospitalization facilities expose people to or varied experiences of seeking care through phases of at the OPD, diagnostic procedures, minor and major surgical interventions, and short or long hospitalization stays. Small private hospitals, nursing homes and polyclinics with small bed strength (5-30 beds) also are other major sites of these interventions, OPD and IPD care. As against one district hospital as a single unit, private hospitals are far more in number, a couple of hundred. Therefore, the experiences narrated about the private sector are across several hospitals not at any one private institution.

The experience narrated of these private institutions and government medical college hospitals providing specialized OPD, IPD, diagnostic, surgical and other curative services was a mixed bag-some happy experiences of recovery and restoration to health, some unresolved illnesses, some sad loss of lives, some of gentle and sensitive care without causing a financial burden, whereas others were stories of struggle, conflict, huge costs, feelings of being cheated or betrayed and of bankruptcy. Shambhu's experience of limb paralysis after a road accident and denial of treatment by government hospitals catches this myriad of experience with different health institutions to some extent. *Shambhu after a vehicular road accident was taken by passers-by to the nearest hospital SDH-Mukhed, he was given first aid and advised to go to the district hospital. Unaware of the seriousness of his condition, Shambhu decided to go home and visit the hospital in Nanded if his condition did not improve after he had managed to mobilise some money for treatment if needed. After two days at home and realizing that he was suffering from paralysis of the lower limbs, he organized for some money and decided to visit the private hospital of Dr. Pagare. Dr. Pagare had worked as Medical Officer, a general surgeon at RH Kandhar and was a well-known doctor also known as a good doctor in the block. He along with*

some other doctors had started a private hospital in Nanded. Reassured by his faith in Dr. Pagare's name, Shambhu decided to visit his private hospital and was admitted there (Aksha hospital – a private hospital) for 3 days. After the initial examination he was told that he might need an operation on the cervical spine. After several blood and radiological investigations like X-ray of the neck and MRI (costing around Rs.4000) of the cervical spine he was informed ***that they would operate on him in the cervical spine region, and kept him admitted for two days. (It was unlikely for them to have had an expert surgeon and the OT setup that a cervical spine surgery required). Shambhu now doubted the capacity of Aksha hospital to undertake cervical spine surgeries since he had been told about the difficulty, lack of expertise and amenities even at KEM hospital, Mumbai during his visit. Later he was informed by the doctors at Aksha hospital that the operation was too expensive and was referred to the district hospital*** *in the same city which was attached to a government UG and PG medical college. After a couple of days of admission at the medical college and district hospital at Nanded, he was advised to visit the medical college hospital at Mumbai. He travelled to Mumbai in the unreserved train compartment, sleeping on the floor. He was admitted in G.S. Medical College and KEM hospital after several requests, waiting and finally through the connections of a known doctor. After a couple of days of admission there, he was discharged with a neck collar and advised to use a water bed. He returned home after going through a chain of hospitals ranging from the SDH Mukhed, the government medical college and district hospital of Nanded, a private multi-specialty hospital and the state's top ranking GS medical college, KEM hospital at Mumbai. He was not sure about the condition he was suffering from, and no one had explained it to him; neither had been told of the prognosis of his condition or future course of action.*

After six months at home, Shambhu could move his hands and legs, after which he decided to consult a doctor, and following the many suggestions from friends and relatives he visited the Government Ayurvedic medical college and hospital at the district headquarter, Nanded. There ***he was admitted for almost 2 months (the institution provided long-term indoor care, and was not trying to get rid of him quickly, unlike other places)****. In this hospital* ***for the first time, he was explained the nature of his illness, and its prognosis****.*

Among all the doctors he had taken treatment from, and institutions he had approached ***he preferred the Ayurvedic hospital and its doctors. He had experienced improvement there and***

though not completely cured he recovered partially. *In the Ayurvedic medical college, hospital* ***doctors were considerate and concerned, and treated him as a person and made time in their daily schedule to talk to him and other patients, explained the nature of the illness, its prognosis, and precautions he needed to take post-treatment.*** *The* ***doctors and institution were in no hurry to get him out of the hospital****, they were* ***ready to keep him as an indoor patient for one more month till he improved significantly***. *It had been difficult for him to get admission in* ***the government hospital***. *The* emergency OPD at SGSMC, **Nanded and KEM hospital,** Mumbai had made him wait for long, and he had managed admission in the later only through a connection. And though admitted at the government hospital he was discharged in a couple of days without any information about the nature of his illness, or experiencing any recovery from illness.

Later at SGSMC Nanded he **could not get admitted in the hospital for getting his bed sore, that he had developed during the course of his illness, treated**. *He had spent the entire day at the hospital where he was made to go through different OPDs, he subjected to different tests including X-ray chest, USG abdomen and some blood tests. At the end of the day, late in the evening he was given a written prescription and advised to wash the sore and apply medicine. (It appeared as though he was made to go through those tests just to avoid cleaning and dressing of his foul-smelling bed sore.) His explicit and repeated request to have the sore dressed was rejected and he was asked to leave the hospital premises. With no conveyance or transport available at that time from Nanded to his village and due to the pain of untreated bed sore, the paraplegic Shambhu felt very helpless. He had to beg to be was allowed to spend the night in the hospital premise sand was shown the gate early morning.* Thus, there was a **tendency to avoid treating a case that involved some effort and hard work by the doctors. There was a tendency to take the patient out of the hospital premises as early as possible, irrespective of whether the patient got relief from his symptoms or not**. In his case, doctors did not even show the curtsy to dress his ulcer, if the doctor were given the benefit of doubt at best it was may be because the OPD timings was not when the dressing was usually done.

In the morning he had visited the Ayurvedic medical college with the hope of getting his wound cleaned and dressed, but here he was told that the dressing of such a wound was not their specialty, and he needed to be treated using modern medicine. He was once again referred back

to the government medical college and district hospital. (It is pertinent to mention here that the Ayurveda medical college has training in modern medicine too and have a fully functional OT, performing some elective surgeries.) He spent the entire day in pain, helpless on the street till evening when he decided to explore a different alternative.

Given his financial limitations, he opted for a trust hospital which ran on a no-profit- no-loss basis, Tayar hospital where he was admitted for a month and diagnosed as having a sinus. He was then dressed regularly and given some medicines and antibiotics. ***He had spent almost 20-30 thousand at Tayar hospital for medicines, hospital stay and food for himself and his family members attending to him. During this one month and two weeks stay at the hospital, his entire family had gotten disturbed yet again and things were in disarray.*** *It affected the schooling of his children and the health of his parents as there was no one to take care of them. He had to sell off part of his land to meet the expenses of this treatment. Further he went on to say that* ***if the government doctor had shown the curtsy to treat him, his land, the only source of livelihood for his whole family would have been spared.***

Talking about his experience in Tayar hospital, the not-for-profit trust hospital, he said that ***most the doctors there were visiting consultants and the*** *treatment orders given by them were usually followed. However,* ***their visits were few and not very regular. So, changes if needed during the course of treatment would get affected****. However, the* ***hospital was good for the poor people as it provided treatment at minimal costs and it was providing care without trying to get rid of a poor patient before they experienced relief from their ailments****.*

Shambhu was very hurt and had lost faith in medical professionals given that ***none of the doctors from the allopathic system of medicine both in the private and government sectors ranging from sub-district to apex level hospitals in the capital city of the state gave him simple and crucial advice*** *of exercise and massage or advised him about physiotherapy. Pointing to his contractures and wasted limbs he said that could have been avoided. He recollected the advice given at KEM hospital in Mumbai and said that following their instructions his family members and he himself had made sure that the waterbed was constantly shaken, so he did not have any bed sores in the first year of his illness.* He was trying to explain how he was a very compliant and sincere patient, willing to follow the doctor's instructions. besides feeling pained at not

receiving proper treatment for his condition, Shambhu was disappointed by the insincerity of medical professionals at different levels who had not even shared simple oral advice that was to be followed at home, that could have saved him from contractures.

Shambhu's experience covered a CHC, three government medical college hospitals (of which one was the top-most in the state, one was a government ayurveda medical college hospital), one a multi-specialty private hospital and the last a not-for-profit trust hospital. This experience brings out the helplessness that he had to go through; the pain he had to endure, aggravation of his suffering due to lack of proper advice, the reluctance to treat or denial of treatment, lack of clear dialogue with the patient to explain the nature of the disease, its prognosis, likely treatment options and possible outcomes/complications, the impoverishment and in Shambhu's story in particular, treatment for paraplegia leading to bankruptcy. His case–paraplegia with some injury at the cervical spine also happens to be an unusual and rather difficult case to treat for most medical professionals, except for experts of spine surgery. The treatment options are few and have limited success rates and the prognosis is usually poor, difficult to predict and even more difficult to convey the limits of knowledge and skills of medical/science and professional to deal with such ailments. It would be challenging to convey the grim reality of complete paraplegia and some permanent weakness even of upper limbs to a young man who was the sole breadwinner of family. His bed sore, foul smelling, possibly infested with maggots (this could not be confirmed to avoid him embarrassment in front of his children, neighbours and friends who were present at the time of interview) was according to him an unusual occurrence in the present time and a tedious task for doctors to clean and dress. Given that his disease condition was rather unusual and the difficulties of treatment it possibly compounded his sense of demoralization and made him feel hurt. Though his disease condition was rare, his experience of going through the treatment process echoed popular perceptions/impressions and experiences of seeking care in government and private hospitals. To understand further, the overall experience of seeking care institutions at multiple levels of the health care system, Ujala's case- she had a head injury, a chronic urinary tract infection (UTI) and dysmenorrhea; is discussed here.

Ujala *had been taking treatment for her symptoms of burning during micturition, and dysmenorrhea from the PHC in the village for more than 10 years.* ***She had consulted many doctors posted at the PHC at different times. She had been prescribed different medicines at***

different points of time by different doctors. The treatment had mainly consisted of few oral tablets and capsules. *She has consulted several doctors primarily for the burning she felt during micturition and dysmenorrhea.* ***Over time she had reduced her number of visits to the PHC since the treatment given did not offer much relief. Ujala's overall experience with the PHC in terms of relief and cure had been poor. She said that the medicines prescribed by the PHC were of no use and did not relieve her of the symptoms.***

In the past 10 years she has also visited several private practitioners in Kandhar, visiting them once every one or two months. Going to Kandhar for treatment had almost become a routine for her. ***In this long period she has visited almost all, about seven to eight private practitioners in Kandhar. The treatment consisted of different tablets, capsules, syrups, injections and IV fluids. Many a time the treatment was also accompanied by urine and blood investigations. She had experienced partial and temporary symptomatic relief due to the treatment by private doctors.*** *However, her overall experience with the private practitioners also had been one that did not translate into much improvement.* ***Many a time, she got no relief and whenever she did, it was partial and short-lived. She had spent a significant amount of money, time and energy in the pursuit of getting better at Kandhar****.*

She consulted a gynaecologist in Nanded, got her USG abdomen done and had been informed of a fibroid in the uterus and advised hysterectomy. When she informed the doctor about her past history, of a head injury and resultant unconsciousness, she was told that she could get the hysterectomy after waiting for a year and was given medical treatment not operated upon. The cost of the hysterectomy they had suggested was out of Ujala's reach too. She completed the prescribed treatment diligently but did not get any relief from the symptoms. Later, while they were in Pune, working as migrant workers, she consulted a private trust and teaching hospital, popularly known as Jawale hospital and a private hospital. Jawale hospital was a big multi-specialty trust hospital with a medical college in Pune. *She consulted the gynaecology OPD for her complaints of burning micturition, heavy bleeding during the menses and white discharge. She was advised to undergo a USG abdomen and pelvis along with blood and urine tests there. She was charged 800 Rs. for the blood tests. On visiting the doctor again with the USG report, she was* ***advised a hysterectomy, that would cost her Rs.*** *17-18,000 Rs.* ***She wasn't explained her exact condition or given a diagnosis. She was only told that she would need an***

operation and the charges for the operation were given to her. Ujala's family had spent *Rs. 1500 Rs. for this advice from the Jawale hospital at Pune.* The available medical records of the USG pelvis documented no abnormality in uterus. It was a USG report with normal findings from the abdomen and pelvis.

On asking whether she had ever visited the government medical college and hospital at Nanded, she said that in the past, she had been taken there and admitted in the government medical college and hospital for her head injury. The injury had been caused by a stone kept on the tin roof falling through, on to her head while she was asleep. ***It was a major head injury, that caused her to become unconscious. She was immediately taken to RH Kandhar, where the doctor referred her to the government medical college and hospital at Nanded. She was taken in a privately rented vehicle to Nanded immediately where she was admitted in government medical college and district hospital where she was started on injectable medicines and IV fluids, and underwent blood and radiological tests including a CT scan of the brain. She was admitted there for 5 days, by when she recovered and was discharged on the fifth day. The total cost of care including the CT scan, some medicines and other consumable items from outside was about 3000 Rs. The overall experience of the government hospital had been good and she and her family thought of it as a better hospital than others.*** *Despite this good experience of recovery from a life threatening and serious condition, she did not visit this hospital for her chronic problem of burning micturition and dysmenorrhea, possibly because it was inconvenient and the treatment process was time-consuming. She may not have been done with the consultation and investigations in a day and the combination of distance, lack of transportation facilities and the timings of the hospital may have deterred her. The limited impact of the medicines offered at the government run PHC might have led her to believe that the same medicines would be offered from all the government hospitals leading her to avoid the government hospital, including RH Kandhar- which she may have crossed many times when visiting the private GPs for consultation.*

She further said that her experience of five days at the **government district hospital,** ***was overall, an experience of better care. On asking why she felt that way given her and her family's scepticism about the care given at government hospitals, they said they what else could they want when she had recovered from a very serious and life-threatening condition.***

Recovery from the condition was of paramount importance when people assessed a government hospital as good and providing good care. *Commenting on the total cost of care at the government hospital they said that they had to shell out very little money as compared to the private hospital. They had spent around Rs. 3000 at the government hospital, , and most of it had been for the CT scan.* ***So, the cost of care though high, was much less as compared to what they would have spent had she been admitted in a private hospital. Hence cost considerations were another important factor behind rating the government hospital better than others****.*

While she (Ujala) had been either unconscious or sedated for most of her stay in the medical college hospital at Nanded, ***she had little complaints about the hospital staff or their behaviour even from the times when she was conscious. Her husband, who had been attending to her, shared her opinion and said that with respect to the staff and doctors' behaviour they did not have any bad experience.*** *However, they had earlier in the interview complained generally about the poor health care services and inhuman and undignified treatment at government run health institutions.* This was an opinion and image of government run health institutions shared by the community. This divergence between impression and experience could partially be because of the inconvenience and poor experience in receiving care for routine and minor illnesses requiring OPD care, as against the indoor care received for serious and life-threatening conditions. It was also possible that the behaviour of health care providers also changed towards seriously ill patients.

3.2.2 Experience with different health care providers (Healers, ANM, MO-PHC, private practitioners, MO-RH, specialist doctors (public/private, nurses, physiotherapist, ayurveda doctors, ayurveda medical college)

The experiences became health care provider centric usually at the institutions at the lower levels, like the GPs running private clinics or the small nursing homes and the PHC. The RH and district hospital experiences were usually articulated in terms of institutions unless there was some health care provider who made some impression (usually good) and was famous. This was observed only in the case of a couple of medical officers from the RH, who were often identified as good doctors and their names were known to many in the block.

Doctors at tertiary hospitals

The health care experience at the district hospital was referenced in narratives by the institution and in some cases, very few though, there was a reference to professionals from tertiary health care institutions like medical college hospitals too. *With suggestions from friends and relatives Shambhu visited the Government. Ayurvedic medical college and Hospital at the District Headquarter Nanded for getting an opinion and starting treatment for his paraplegia again after a gap of six months (he had earlier taken treatment from the CHC, and medical college hospital at Nanded and Mumbai). Here he was admitted for almost 2 months. For the first time he was explained about the nature of illness, and prognosis here.* ***He was informed for the first time that he had an injury to his spinal cord, what the spinal cord was, its structure and function, the chances of improvement and precautions he needed to take and the exercises to be done. Here doctors cared to talk to him, spend some time to explain the nature of illness and some doubts he had in his mind****. (During his two month-long stay in the hospital he got Ayurvedic treatment which consisted of Ayurvedic medicines and mainly different types of massages and a kind of hot fomentation using herbs and oils etc. The personalized care in this government hospital made him feel cared for.* ***Doctors and other hospital staff were talking to him, spending some time with him, helping him in doing his exercises, there were professional masseuses available, though they were not hospital staff and had to be paid for from his own pocket. They massaged patients of different kinds of musculoskeletal disorders and paralysis****. These massage sessions had a great deal of importance in his experience of illness and treatment. He* ***felt cared for, and that somebody was investing time, energy and skill to get him better.*** *He* ***was told about the importance of massages and exercises****. He had already developed contractures in his palms, elbows, feet. Hands and lower limbs had undergone some wasting. With the massages and herbal hot fomentation his condition improved, his contractures had shown some relief and with more power in both his limbs, he could stand with support.* He highlighted how health care providers were sincere in their efforts to treat him and had treated him like a human being.

Doctors at the block town (GPs and medical officer)

At the block town level, the bulk of health care was received from general practitioners. They were major health care providers for most villages around the town and provided OPD care.

Most of the health care experiences were articulated and anchored in that individual practitioner. The GPs had become major health care providers over previous two decades, prior to which there had only been 2-3 private practitioners. The GPs were serving the purpose of providing care for most of common and minor illnesses and the fact that community consistently took recourse to them showed that they were of some help in providing them relief from their ill health and suffering. However, expectations of relief from symptoms from doctors in the government and private hospitals differed. Given that people spent money on care from private practitioners, they did not really complain or demand accountability and if the treatment did not give them intended results , they simply changed the GP during their next visit. *Sumangal's baby was showing signs of abdominal breathing with high grade fever and cough. Mother sought sister's treatment later decided to take the baby to Kandhar. In Kandhar she visited Dr.* ***Gudewar's (****a BHMS doctor) private clinic. The doctor was chosen because they were familiar with him, since he was a visiting private practitioner at Panshevadi village since couple of years.* ***He reassured her that the baby would recover by the night and sent her away with some medicines a syrup and an injection and sent them away.. The baby was given these medicines for two days but there had been no improvement in condition****. She took the child to Kandhar once again, to another private practitioner who was well-known as a child specialist in the town and surrounding villages,* ***Dr. Gudwane a BAMS doctor, gave a new set of syrups and one injection that she gave to the baby for two days. There was no improvement in the baby's condition, d***espite the time and effort spent at the private practitioners' clinic and on travel, consultation and medicines. However, they did not really seem to demand accountability from the private practitioners. This may have been because the illness later required treatment from higher centres with the help of specialist doctors, after going through blood tests and other investigations. This might have given them an impression that the disease was serious and beyond the capacity of private practitioners. The expectations from the private practitioners were only of immediate and convenient treatment for common illnesses. In case of no relief from symptoms after treatment they usually changed the doctor in subsequent visit.

At the block town, some RH health care providers had become part of community memory as dependable and good doctors, nurses. There were many interactions in the community formal and informal, where some of the past medical officers and nurses were mentioned with respect and their names were invoked, suggesting that they were good doctors who made the RH an

institution where they could seek medical care. Some of the names included were Dr. Pagare, Dr. Ghardive, Patel sister, and Dr Sugadekar. Some of these providers and their experience have been discussed in next chapters also. *While discussing functioning of the RH at Kandhar he (Sumangal's relative) once again invoked the doctor's behaviour as an important criterion.* ***He said, that the current medical officer Dr. Sugadekar was good doctor with manuski (humane behaviour)- he had taken a relative for treatment to the doctor and Dr. Sugadekar had spoken to them politely, and with respect. Their patient also had recovered following his treatment.*** *He would contact the doctor on the mobile, to inform him of their arrival whenever he had to accompany a patient to Kandhar RH, in case of emergencies.* ***Dr. Sugadekar usually would be at the hospital before them or else they would call him once they reached there, attending to them without delay. He spoke to they properly, explaining to them their condition and if needed asked for medicines from outside and treated their patient or gave necessary advice in case of referral****. Sumangal's relative recalled* ***"if I or any other person from the village happened to meet Dr. Sugadekar anywhere outside the hospital, he recognizes us, talks to us respectfully, enquires about us".*** **They saw the doctor as somebody to treated, a medical officer of the RH as well as a nice person, beyond his professional capacity. The connection and familiarity they shared with him as a nice person with a human nature, i.e. manusaki, helped them have faith in him easily, and had helped develop a relationship of mutual trust and faith. This was substantiated by his professional skills in relieving the suffering of the patient and offering him proper advice in a satisfactory manner which people understood.**) *On probing further, he explained that people visited doctors who did not* ***talk much but treated correctly, only in dire need. They avoided unnecessary talking to the doctor as they had confidence that their patient would get appropriate treatment and get better****.* ***"If we see the doctor making an effort in examining, investigating and treating the patient then we don't disturb him, it is only when our patient continues to suffer and doctor does not even bother to attend and do something that it raises doubts in our mind."***

When asked who his favourite doctor was, Amol's father said that being relatively better off, he (Anmol's father) got good treatment from most doctors he visited. ***However, he went on to add that doctors like Dr. Sugadekar, who came from humble socio-economic backgrounds themselves were the ones who more are liked since they were more likely to be sensitive in their behaviour and were in a better position to understand the condition of the patients and***

their suffering. The perspectives of doctors in diagnosing and treating the patient differed and doctors coming from humble socio-economic conditions were more likely to understand their contextual realities and keeping those in mind whole treating, advising and behaving with patient and their family. *For Anmol,* ***Dr. Sugadekar, the RH medical officer, had given them some medicines to try and had advised them that if the condition persisted after the completion of the course of oral medicines, then they might have to consider the option of starting him on the long course of the injection penicillin. Dr. Sugadekar had informed them of the possibility of developing a condition which might affect the heart. The same concern had been echoed in the recent past by the PHC medical officer, Dr. Gedam as well.*** *Initially they avoided treating with injections for fear of side effects, inconvenience and painful treatment. They were told that the injections had to be taken for almost 10-15 years.*

Some of the memories of some doctors were from the distant past- remembered as sensitive and good doctors. *Krish's uncle* ***recollected the Dr. Ghardive who was the MO 15 years prior to this study used to take responsibility for the patient and treat them, if he could not manage the case. If there was need, he used to refer the case to higher levels and make the effort of calling and reporting at higher levels where the patient had been referred to, to inform them about the his/her condition. This acted as a great support for people who approached her. The referred patients used to get admission without much effort, based on the earlier discussion that the medical officer might have had with Dr. Ghardive****. He commented further that the current doctors were not clear about treatment decisions and went on to say* ***that if the doctor was getting his education by paying money or getting his degrees by paying money then he was less likely to be good doctor. According to his analysis one of the important reasons for not taking responsibility was that the current doctors were professionally less sound as compared to earlier ones. He believed that most doctors, (not all) were getting their medical education in private medical colleges by paying money. In private medical colleges they got less experience and were less likely to be confident in taking responsibility for a patient.*** *He compared them with school teachers who themselves understood little but had gone on to become teachers and were teaching. He said that many boys had passed their examination by cheating and went on to become teachers who could not even do a simple calculation.*

These experiences and expressions about their health care providers brought out the attributes that they desired in their health care provider. While it was assumed that a qualified doctor would have basic scientific knowledge, it was expected that the doctor also know the patients' contextual realities; be sensitive towards them, advise them in a manner that they could comprehend and act on; provided some handholding and guidance in navigating the complex sphere of health care institutions; someone who put in sincere effort in relieving suffering; someone who gave them confidence and assurance; acted as a bridge between them and higher levels of experts and institutions; someone with whom they could have functional conversations as fellow human beings and expect humane behaviour (manuski) during that delicate phase of ill health and suffering.

Doctors at PHC

The health care experience at the level of the PHC was dependent on the doctor (health care provider) present there (as against recommended medical officers, usually only one medical officer was employed and present at the level of PHC) and this experience was articulated usually in name of the doctor. Most of the time the doctor employed at the PHC did not stay in the PHC headquarter village, as was required of him, so the experience of that doctor was limited to routine OPD care. *Ujala chose to go to the PHC because of Dr. Gedam who she described as* ***a good doctor, who talked nicely and gently, listened to the patients' complaints and gave effective medicines that relieved symptoms. This had been the past experience of many villagers, her included. Someone from the village also said that many women went to the PHC whenever Dr. Gedamwas on duty.*** *There had been an overall increase in the women attending the PHC since Dr. Gedam had joined back.* ***He had worked for many years in the village during which he had developed a good rapport with the people. Many including Ujala had said that they trusted the ability, advice and judgment of Dr. Gedam in treating common illness.*** *Sumangal and Krish's mother, both, compared Dr. Gedam with earlier doctors i.e. Dr. Surwade and Dr. Chawla and said that* ***all the women in village avoided the earlier doctors, and whenever Dr. Gedam was on duty, women made sure that they told other women about his presence so that they could also get treatment from him****. Hence, within the* ***given infrastructural facilities, doctors with similar qualifications or in fact a doctor with a BAMS degree was chosen over an MBBS doctor because of his attitude and behaviour.*** *Both Dr. Gedam and Gavade sister, from PHC Panshevadi, were known to this village since long time.*

Dr. Gedam had stayed here for several years as a PHC medical officer few years back. He knew the people in the village and their conditions since he had stayed there with his family. He had earned the faith and trust of the village people. Gavade sister belonging to another village had been working as a staff at the Panshevadi PHC since a long time and unlike the other sister, she resided in the village, and was available all the time. She too had earned the people's faith and trust.

Auxiliary Nurse Mid-Wife (ANM)

Some PHCs had one or two nurses (ANMs) living in the PHC campus and a few names that were mentioned by the community members in multiple interviews were of sisters who happened to be working in those PHCs for a longer time and are stationed in the village. The experience articulated by community members, especially women from the village about these ANMs was about services related to maternal care. *During her first and subsequent pregnancy* ***Sulekha visited the PHC and was again seen by Gavade sister (ANM). She went through same set of investigations and examinations and was given similar advice and same sets of medicines like the first time (100 FS FA tablets).*** *She was not given any special advice or prescribed any special investigation give her previous history of a caesarean section. This might be due to the fact that in most cases ANC was given by one institution (at the in laws place) and the delivery was conducted at a different place and institution (usually in the natal home). Sulekha's father in-law recollected that his wife had been operated in the PHC Kurula, where they remembered* ***one good nurse, Adhav sister****.* She had been working and living at the PHC for many years and was well known for her skills in ANC and delivery-related services.

Private sector doctors

Specialist from district town

The private sector dominated health care provision for people of Panshevadi, addressing most of their care needs. GPs from Kandhar town were approached for most of their routine health care needs and some of these experiences have been discussed earlier and in other chapters as well. Health care from specialist doctors in Nanded was another major part of community memory. Though not as frequent an as treatment from the GPs, private specialists left an impressionable experience and contributed significantly to their care seeking experience. This experience was many a time related to OPD care and was sometimes also of hospitalization care. The

hospitalization experience, due to its very nature had a lasting impression on their minds and became a part of the discussion and contributed various dimensions in understanding the notion of quality in health care. Most of these experiences have been discussed in subsequent chapters. *Ujala and her husband, based on the experience and suggestion of other community members in the village, had gotten to know about Dr. Trishila who they decided to consult for her problem. They went to Nanded, waited in queue at the OPD of her nursing home.* ***Dr. Trishila examined her, asked her about her complaints and performed an ultrasound examination of her pelvis. She also ordered some blood and urine tests. After doing her USG pelvis she told her that there were masses (fibroids) in her uterus for which she would need a hysterectomy at the earliest to get rid of her symptoms. Ujala's age when she was advised hysterectomy was around 30-32 years and the charges for the operation were about Rs. 10,000 Rs.*** *Ujala expressed her inability to gather so much money within as short period of time. During the course of inquiry about past history, Ujala told the doctor that she had a past history of head injury accompanied by loss of consciousness two years prior. Dr. Trishila then advised her to get the operation performed after a couple of years.* ***She said however that she would need hysterectomy as a final treatment whether done right then or after some time. The USG report was not available since it had been performed in her own nursing home. It was possible she might not even have given a printed report to her, or they could have lost it. (However, a subsequent USG report done from Jawale Medical college hospital at Pune was available and it showed no abnormality with no mention of fibroids in the uterus.)*** *She was prescribed some medicines to take for a month and went back to her village, completed a month-long course of treatment that* ***gave her very marginal partial symptomatic relief. She continued the same medicines for six months, buying them from the market; after which she stopped taking them since she thought of it as futile expenditure on useless medicines.*** Hence being offered affordable services and treatment that provided relief from the symptoms was an important consideration in assessing the experience of care provided.

Traditional healer

Affordability of services and relief from symptoms with prescribed treatment were basic essential elements in assessing the care seeking experience with a health care provider for most community members. In addition to these elements, humane behaviour (manuski) and sensitivity and earnestness in providing care also constituted important elements while evaluating health

care providers and the care provided. Attributes like moral and ethical standard and an attitude of selfless service in health care providers, irrespective of their qualification, were also used by community members in their judging a health care provider and the care they received. *Asaya was treated for a poisonous snake bite and was treated at the medical college and district hospital at Nanded, that saved her life. She was discharged with an advice for a follow-up visit. After discharge she developed swelling and edema in her entire legs, from the foot to the knee. The area turned black and numb and swelled with blisters that were growing rapidly. They had sought Dr. Shende's opinion. He was a famous snake-bite specialist in the area who advised them to go to Nanded and take treatment, warning them of a possibility of having to amputate the leg of she did not respond to the initial surgical line of management. Madhukar, her husband, had heard about a herbalist, also known for treating snake bites in the village Bomnali that was nearby. . The couple reached Bomnali, by bus.* ***. Healer first asked them to visit the local temple dedicated to Hanuman and offer prayer and one coconut at the temple before starting the treatment. He said he would not charge them anything for the treatment, however they could offer what they liked at the temple, depending on their economic capacity, if at the end they were satisfied with it. He did not need to to know what they offered.*** *They did as they were told and went to the Hanuman temple, offered prayers and broke one coconut in front of the temple, before coming back to him.* ***He asked them the history of events and description of the snake.*** *They told him what had happened before and after the snake bite, including the history of treatment taken at the government hospital and advise given by Dr. Shende.* ***Meanwhile he took out one photo album to show them many pictures of snake bite patients who had taken treatment from him. The album contained the picture of the bite site before starting the treatment and at the end of the treatment. The photographs had the patients' addresses written on them. They saw many pictures of bite injuries of varying severity. Some of the pictures showed larger wounds than Asaya's. In most cases the wound had healed completely at the end of treatment. This album gave them some confidence and served as evidence about the provider's ability to treat her.*** *He then examined the site of the bite, where skin over the region of her ankle had turned into a large discoloured, almost black anesthetized patch.* ***He touched and pressed the affected area, which was completely without sensation because of which she did not feel much. He then brought out a sharp object and started to dig into the affected skin, removing blackened tissue by cutting it from the site with the sharp object in his hand. He***

then gave her a sharp glass object asking her to remove the skin and tissue from the affected site. *She and her husband were able to remove the remaining discoloured tissue from the affected site since it she was not feeling any pain. Deep tissue, which was soft and flabby, was also removed from the site. The whole area now turned into a large ulcer covering most of the dorsal side of foot, till the lateral edges of the sole, and few inches above the ankle joint.* ***He then told them that he would give them some herbal medicine to apply on the site which would restore sensation in the affected area after one to one and half weeks' of treatment. He then took a piece of wood piece, most probably a root or stalk of some plant, and rubbed it on a stone with a small amount of water and applied the resultant paste on the affected area. He gave them the root and asked them to apply the medicine in the same way twice daily for the following week and return after a week to take the next batch of medicines.*** *They returned to their home and applied the medicine on the affected area over the next one week during which the wound dried significantly and there was considerable reduction in the secretions as well.* ***They returned to the herbalist a week later when he examined her wound and gave her the same medicine to apply for the following week. This time he also gave them a powder to be applied to the wound once a day. It was Neosporin powder. They now applied the paste from the twig/root twice and the Neosporin powder once daily. The wound was dry at the time of the interview and*** *one could not comment on the status of the ulcer as it was smeared with the paste. The edges of wound had rounded, and the ulcer was large in size, indicating that it had a long way to go before complete healing. The herbalist had asked them to return for a follow-up for visit the following Tuesday. According to him she would need two more weeks of treatment after that.* ***On asking about the improvement in her condition Asaya said her condition had improved and she was satisfied with the treatment she was receiving. She said that she used to do routine work in the house initially after the discharge from the hospital, since her foot did not bother her, though there was the large black patch. However, with one to one and half week's treatment now she had started regaining sensation in her foot, as predicted by the herbalist, and she could not work like she used to, because of the pain. Hence, to them it was a sign of improvement. The ulcer had dried up and they were happy because her condition had improved without them having to spend much money, definitely little when compared with what was suggested by Dr. Shende.*** *The expenses he had to incur for this treatment consisted only of traveling cost which was around 120 Rs per return trip, for two persons. Recollecting the*

experience with Dr. Shende she said that he had charged them 100 Rs just to tell them that she would need treatment at Nanded and would have to go there. All he did was suggest the name of a doctor with a private hospital doctor in Nanded.

3.2.3 Summary

Table 3.2Desirable and Un-Desirable Aspects of Experience and Expectation from Health Services Based on Overall Experiences of Care Seeking

Desirable aspects of experience and expectation from health services	Un-desirable aspects of experience and expectation from health services
System structure of health services • PHC serves as dependable institution to provide ANC check-ups for pregnant mothers,	• Inconvenience due to its long distance DH and specialist services of around 70 Km from their village.
• **Attributes and features of provider** • Doctor acted very swiftly and earnestly • Treated without any delay and required treatment is given • ***Doctors and other hospital staff were talking to him, spending some time with patient, helping him in doing his exercises,*** • ***Patient felt that he was cared for, somebody is investing time, energy and skill to get him better.*** *He* ***was told about the importance of massages and exercises***. • Providers were sincere in their efforts to treat him and had approached him as human being. • ***Doctor with manuski (humane behaviour).*** • ***This doctor had spoken them politely, satisfactorily and with respect. Their patient also got well with his treatment.*** • ***Dr. usually comes to hospital before them or else they will call him after reaching there, in that case doctor attends them without improper delay. He speaks satisfactorily, explains them about condition and, asks for medicines from outside if needed and treats their patient or gives necessary advice in case of referral***. • ***If patient or any other person from the village happened meet the doctor anywhere outside the hospital, he recognizes us, talks***	• Insincerity of medical professions at different levels of giving treatment and even in giving a plain simple oral advice to be followed at home,

to us respectfully, enquires about us". • **Thus Dr. is known to them as a treating doctor, medical officer of RH as well as a nice person beyond his professional capacity. This link and familiarity with him as nice person having human nature i.e. manusaki, helps them having faith in him easily, developing the relation of mutual trust and faith. This is substantiated by his professional skills in relieving the suffering of the patient and giving proper advice in a satisfactory manner which people can understand.**) • ***Doctors coming from humble socio-economic conditions are more likely to understand the contextual realities of the patient while treating, advising and behaving with patient and their family.*** • ***Doctor used to take responsibility of the patient and treat them*** • ***Doctor used to take efforts of calling and reporting at higher levels where patient was referred about the given patient's condition. This acted as great support for the people. The referred patients used to get admission without much efforts based on earlier discussion with medical officer*** • Doctor should also have knowledge about contextual realities of patient; he should be sensitive towards it; the advice given should be such that they can comprehend and act on; some handholding and guidance in navigating the complex sphere of health care institutions; someone who put in sincere efforts in relieving suffering; someone who gives confidence and assurance; someone who acts as bridge between them and higher levels of experts and institutions; someone with whom they can have functional conversation as fellow human and expect humane behaviour (manuski) during that delicate phase of ill health and suffering. • Humane behaviour (manuski) and sensitivity and earnestness in providing care also constituted as important elements while evaluating health care providers and the care	

provided. • Attributes like moral and ethical standard and selfless service provisioning attitude of health care provider, irrespective their qualification, also were used by community members in judging a health care provider and the care provided.	
<u>institutional features</u> • ***It provided treatment at minimal costs*** • ***Hospital premise and delivery room, ward were appropriate and well maintained*** • ***Doctor was present in the hospital at the time of delivery; he had examined her ones before delivery,*** • Availability of drugs, medicine and other consumables required, availability of doctor in PHC, skills, sincerity and earnestness of the doctor there. • ***Doctors cared to talk to him, spend some time to explain the nature of illness and some of the doubts he had in his mind***. • ***Improvement in her condition without spending much money when compared with what was suggested by other doctor.*** • ***The cost considerations were another important factor behind rating the government hospital as a better hospital***.	• It was a challenging task to be a patient of government hospitals, especially in secondary and tertiary hospitals • Timings and limited number of OPD registration • Sizable number of people could not get that OPD paper. • Lack of availability of beds. • Refusal of not having an ailment of interest of the health care provider • Cost of care at private hospital are too prohibitive • The process of becoming a patient for person with illness is cumbersome, confusing, time and resource intensive • Navigating the maze of infrastructural space, bureaucratic processes, internal divisions and referrals, institutional process, timings, technical language from very busy, overworked and unfriendly doctors in a time bound manner in a faraway town for rural person is a challenging task. • Insensitive institutional processes and hospital staff. • The dirty and un-hygienically kept infrastructure of the hospital. • **Tendency to avoid the treatment involving some efforts and hard work by the doctors** • **Tendency to take the patient out of the hospital premises as early as possible irrespective of**

	whether the patient got relief from his symptoms or not. • ***During hospitalization number of visits of the consultants was few and not regular. So changes if needed during the course of treatment would get affected***. • ***Spent significant amount of money, time and energy in the pursuit of getting better but still lives with suffering*** • Absence of doctor or lack of competencies and material support for treating the ailment
<u>Medical/ clinical care components</u> • ***Getting better from the condition was of paramount importance in saying that the government. hospital was good and provided good care***	• Pain he had to endure despite treatment • Aggravation of his suffering due to lack of proper advice • Reluctance or denial of treatment provisioning; • lack of clearly articulated dialogue with patient by doctors explaining nature of disease, prognosis, likely treatment options and possible outcomes/complications • Bankruptcy/ impoverishment he had to go through for taking treatment. • ***She got no relief and*** • ***Whenever she got relief it was partial and short lived.***

Chapter-4 Quality Considerations from Institutional Structures and Processes

Introduction

The care seeking experience of community members when studied it was realized that the entire experience can be analysed in terms of different themes that are important to understand the concept of quality in health care. identifying the site of a problem or the strengths of a health care practices or system is possible to enable both appreciation and intervention when necessary. Attributing the problems in quality of health care to wrong causes can lead to unsuitable and ineffective solutions and wastage of resources. To avoid this, it is important to understand how the community thinks about quality in health care by studying it systematically through different themes.

It is important to study community preferences and problems faced in accessing health care in a manner that allows the identification of the exact site of problem.

As seen in the previous chapter the community expected health care providers/doctors to be more sensitive to patients. Doctors who understood the contextual realities of patients they were treating were valued and preferred by the respondents and other community members. They wished for doctors to understand their economic conditions, the distances they travelled to get to the facility, the living conditions and circumstances of rural life, the nature and conditions of work, caste and gender-related issues and the other aspects of their lives that impeded their attempts to be healthy etc. These contextual realities were many a times beyond the control of patient and community members and were the constraints under which they were trying to seek health care. According to community members, awareness and sensitivity about these contextual realities of the patient would help providers in providing better care.

Similarly, as far as health care providers are concerned, there are aspects of institutions that they work in, which are beyond their (personal and professional) control. Patients and attendants when seeking care are concerned with getting relief from their suffering and may not be equipped in this vulnerable time, when they are dealing with ill health, to understand contextual factors that shape the capacities of health care providers.

The contextual factors of health care providers could be discussed in terms of the larger structural factors operating at the more macro health sector or policy level- like that of the state of medical scientific knowledge and medical education, public and private health care provisioning, funding mechanisms etc. or at the level of institutions in terms of different institutional arrangements and mechanisms. Both levels are important and both the levels were invoked by community members while discussing their experience of care seeking. While recognizing the fact that both levels are important, the study focuses more on the factors at the institutional level in the form of institutional mechanisms and arrangements to understand people's perceptions of quality in healthcare. The discussion with community members also highlighted these institutional factors more while discussing their care-seeking experience.

The institutional factors discussed here are those which operate above the level of interaction of health care provider (doctor) with patient. Factors operating at the level of doctor-patient interface are discussed in next chapter. The institutional factors governing the services provided in the institutions are discussed below.

The care seeking experience of the community showed that while some factors pertaining to quality were about availability of clinical infrastructure, diagnostic services, human resources, specialists and emergency services etc. others were about institutional mechanisms, rational services, comprehensive services, safe and effective care and institutional culture.

4.1 Convenience-

In discussions on care-seeking experiences and their expectations from health services, community members and patients invariably mentioned the value they placed on the convenience of services offered by health care institutions. Institutions providing services according to the convenience, preferences and needs of patients, were the ones that people considered better and eventually chose. The need and demand for convenient services, was usually inversely proportional to the seriousness of the illness. The probability of adjusting to requirements of institutional processes and the prescribed treatment protocol were higher if the illness was serious. May be if illness and suffering due to illness were serious then all other problems during care-seeking might appear minor and the likelihood of adjusting to the prescribed protocol was higher. If the illness was a minor one then the needs and expectations of aspects (other than relief

from suffering) of the care process became a source of concern, since people had the time and energy to pay attention to those concerns as well. On the whole, the preference for private sector GPs at Kandhar and specialist private hospitals at Nanded was due to the convenience- the ease of access and utilization of services that they offered. The convenience was offered by their centrally placed locations or location at market places within cities, the flexible timings, no waiting time or bureaucratic procedures like having to queue up at different counters and in different buildings for paying fees, getting the papers, consulting the doctor, getting appointments for diagnostic tests, and yet again for getting medicines etc. Respondents and attendants preferred institutions that offered flexibility. The flexibility of-seeking additional information and asking queries about and to the doctor; demanding clinical examinations, receiving treatment according to their needs and demands in terms of specific medicines, formulations, injections and procedures; getting admitted at the hospital on demand and getting procedures and elective surgeries on preferred dates etc.

Private sector GPs were preferred and used extensively for routine illnesses. This preference of GPs over medical officers with similar or higher qualifications, experience and expertise was because the former offered treatment according to the convenience of the patients. GPs catered to patients' and their families' need for early relief from symptoms and that there be no follow-up visits. GPs achieved this by giving patients injectable medicines, newer generation or broad spectrum antibiotics, covering with such blanket therapies for various possible diagnoses. *Keshram had expected to receive the best possible treatment at the PHC. However, most* ***of the times the doctor at the PHC followed a trial and error method- trying one set of medication- a few tablets- and waiting to see whether it brought him any relief before repeating the cycle with the next set. It did not work most of the time, hence he resorted to the doctor at Kandhar. After this experience his family had started going directly to Kandhar to avoid further escalation or deterioration of the conditions they were seeking care for. According to him the doctors at the PHC did not treat many common and simple ailments,*** *the* ***private hospitals were better for minor illnesses where one can get treated and return home the same day****. At the government district hospital in Nanded, it was* ***usually not possible to complete all the procedures related to treatment and return home the same day****. So seeking* ***OPD treatment from a specialist whenever needed and if it didn't work, then approaching a private hospital of a different specialist at Nanded seemed like a practical solution to him****.*

The inconvenience in accessing services offered at the government hospital was a deterrent in utilizing the facilities that it offered. *Commenting on their experience at the district hospital, keshram said that for minor ailments one could not afford to spend a whole day at the district town. Getting treatment from the* ***district hospital involved lot of running from one room to the other, deciphering and navigating the maze of departments in different buildings. One had to start very early from home to collect the OPD paper in time because the hospital only gave out a limited number of OPD papers a day. . It also involved standing in long queues everywhere- for getting signatures of doctors or appointments for investigations, for medicines and procedures etc. Many a time, it was not possible to complete all the procedures related to investigation and treatment in a day since some departments were not open every day and give appointments on an alternate day. If one was lucky then one would be done with the procedures in the hospital the same day, but it meant spending an entire day. It invariably took multiple visits to the district hospital to complete all the recommended procedures or one would at the least get so delayed as to not be able to get transport back to home the same day.*** *All of these still did not assure one of being treated politely and humanely by the* ***doctor or receive a thorough examination and appropriate treatment at the district hospital. They preferred completing the treatment by early evening so that they could go back home by the last auto rickshaw plying to their village from Kandhar town. The private clinic or hospital was thus what they preferred, because they did not have to deal with bureaucratic procedures, they could be done with necessary investigations and treatment the same day or else the doctor would at least give them some treatment as a temporary measure.***

Hospitalization services at government hospital were very cheap or entailed very little direct cost but the institutional processes made the care process lengthy and added to the indirect costs. The hospitalization process at the government hospital at most times did relieve patients of suffering but added to the suffering of the attendants. *Shambhuwas discharged from the Ayurvedic hospital after three months of treatment. The hospital doctors wanted him to stay for some more time, about a month or two longer.* ***However, he requested the doctors for a discharge because of compulsions on the family front. His hospitalization needed someone to stay with him constantly so his wife was staying with him, but there was no one at home to take care of his children*** *and his elderly parents. Hence his entire family was disturbed and in a state of disarray with him and his wife away at the district town. Most importantly the expenditure for the*

attendant especially when it came to food which had to be purchased from outside, was very high. If government hospitals had sufficient support staff, then in many cases attendants would not be required to be present at all times and hospitalization costs would be lower. It would be useful to have some support services from the hospital that would make the long treatments more comfortable.

4.2 Experience with clinical infrastructure and services

The availability of required infrastructure, human resources, services and material resources is essential precondition to provide health care services. These are usually discussed as input or structural factors of the health system and these are also discussed in relation with quality in health care. Inadequate infrastructure, human resources and material resources in the backward region of Marathwada and Nanded district was a widely recognized and acknowledged problem. The infrastructural inadequacies and limited supply of other input-related factors, was common knowledge in the region and also in Panshevadi village, especially with regard to the government run health services. These inadequacies usually formed the premise/ substrate of the community's narratives and discussions on their care seeking experience. The awareness of these inadequacies was sometimes articulated upfront by some community members, while in others' responses was assumed as a given. Most formal and informal discussions with community members repeatedly pointed to the lack of availability of many services in government sector institutions. If available they were usually located very far away or had poor infrastructure, inadequate number of doctors, nurses, support human resources and lacked medicines and other consumables etc.

Among all these inadequacies unavailability of services was repeatedly pointed out as an important impediment. Unavailability of medicines and consumables at government hospitals was a very old problem and people had possibly gotten used to it, so much so that it did not figure as the main problem. The importance of providing medicines at government hospitals was highlighted by a few respondents who said that many medicines were provided from the hospital while they were admitted and that had saved a significant amount of money for them. The government hospitals had been prescribing medicines to be purchased from the market for a long period of time. Private hospitals, prescribed medicines and other consumables to be purchased from the market or a pharmacy store in hospital premises, both for OPD and IPD care. This

practice ensured that patient paid continuously at some other point and the bill that hospital and doctor charged did not come across as a huge amount. The community had gotten used to buying medicines from the market. However, the lack of availability of services meant they had to travel long distances to seek care where they had to pay more by way of consultation fees, transportation and other logistics in addition to medicines and consumables. The inadequacy of services like diagnostics, emergency medical services, indoor services, specialist services, surgical services etc. in the government sector pushes them into the private sector. Unavailability of those services even in the private sector in the towns closer to the villages pushes them to other secondary and tertiary facilities further away in cities, making access more inconvenient and expensive. Unavailability of services mean no care and prolonged suffering. *Mayabai had been suffering from pain in the abdomen, nausea and vomiting for nearly a year. She had sought treatment from many health care providers sorting with the PHC in Panshevadi where the medical officer gave her some medicines. Even though she completed the course of medicines given, there was little improvement in her condition. Repeat visits to the PHC a few more times did not yield improvement. Hence she consulted a few GPs one after the other at Kandhar, completed their prescribed treatments. T**he PHC in her opinion was not equipped to handle her condition** since **it lacked diagnostic facilities.** The doctor did what he could with the medicines available at that level. Mayabai's condition finally improved only after she received treatment based on investigations that were conducted at Nanded.*

4.2.1 The Public sector (PHC and RH)

Inadequacies in health care institutions at the lower level, like the PHC and the CHC/RH were prominent in the discussions with the community members. As the study was conducted in a PHC village the concerns of villages that did not even have a PHC, like Sub-centre villages and of villages that lacked even a Sub-Centre or PHC could not be captured. Their concerns would be greater, with the lack of access to care even for minor and routine ailments or the difficulty of seeking and medical opinion for various health conditions. *Ranpat expressed his displeasure with the services provided. He said that the PHC did not provide even half the services that were available at RH Kandhar. RH Kandhar was considered the reference point for comparison because whenever they went to the **RH Kandhar, besides for emergencies, for routine care, or after they experienced no relief from the treatment at the PHC, the doctors sent them back***

saying that the condition they had should have been treated at the PHC. *They were told by the doctors and other staff at the RH that the PHC was equivalent to the RH and was more than capable and equipped to provide care to the ailment under consideration.* This tussle between the PHC and RH was brought out clearly in many interviews and group discussions too. ***Ranpat then said that ideally there ought to be two doctors staying in the PHC village. He pointed out that there was only one medical officer posted at the PHC who did not even stay there. In his absence there was the inconvenience of getting treatment. One could not be sure of the doctor's availability at the PHC when needed, given their irregular presence at the PHC. Hence, in general the PHC was not seen as reliable source of treatment.*** Thus the problem of limited services at the PHC got compounded by the doctor's reluctance or (incapability) to treat routine illnesses that called for OPD care and referral. The comments from doctors at higher levels had made them realize that the PHC was not acting up to the mark. The lack of availability of resident medical officers at the PHC, in accordance to the prescribed rules of duty, hadfurther limited the availability of curative services at the PHC. The unavailability of the doctor at the PHC in turn made emergency services and expert opinions very expensive to access given that patients had to travel to the block or district towns, that entailed high transportation costs.The availability of only one medical officer at the PHC, as against the norm of two, also limited the services provided. This one medical officer was also expected to supervise the work at all the sub centres, the functioning of national health programs and conduct training, monitor evaluation work, attend routine meetings at higher levels etc. The tasks that a medical officer's job profile entail are difficult to complete. Given the work load it becomes impossible for community members to demand accountability of the medical officer. His absence at the PHC could mean that he was either absent from duty, or on leave or attending to the other tasks assigned to him, which require him to go out of the PHC. The absence of the medical officer at the PHC was a frequent occurrence reducing the already limited set of the services the PHC provided given its inadequacies with respect to supplies and human resource. Traveling to the PHC for consultation would mean a waste of time and money for people from adjacent villages.

Skills and attitude of Doctors

Inadequacies in skill and a poor attitude among doctors and nurses affect many issues at the institutional level, including the culture of medical practice at institutions. The skills doctors were equipped with and the attitude they brought to medical practice were flagged as important

aspects of the care-seeking experience in the narratives care seeking journeys shared by community members. Issues related to interpersonal interactions during the care process are discussed in detail in a subsequent chapter. *According to Krishna's uncle, government institutions in* ***towns and cities had undergone changes in health infrastructure and availability of services but at the PHC level nothing much had changed****. He then added that not all doctors were the same, there were some with manuski (humanity) and others who lacked it did their duty to merely mark their attendance. He felt that in an earlier time a greater section* ***of doctors was humane for*** *e.g., they would, on request attend to the patients at home if they were serious and could not be brought to the PHC.* ***While discussing the overall performance of the system and institutions, a human nature and morality were emphasized, in the context of the behaviour of doctors.*** *Earlier* ***doctors used to stay at the PHC, whereas over time considerably fewer doctors were choosing to stay in the PHC village. He added further that the availability of doctors residing in the village made a significant difference in their accessibility, behaviour and approach.*** *How was the doctor living with the family different from one that lived alone in the village? Dr. Gedamwho was posted at the PHC at the time of this study had been staying in the village with his family for many years as a PHC medical officer and had* ***earned significant trust and goodwill among most of the villagers as was evident from other interviews as well****.*

*The d****octors and hospital staff used to take up the responsibility of the patient while treating someone who was ill. The willingness of the doctor to be responsible for a patient's health gave patients and their relatives confidence, helping further to build mutual trust. In the present though,few doctors were willing to be responsible for their patients causing the latter and their family members to have little trust in the doctors.***

Doctors tended to offer preferential treatment to those who were ***politically influential or had the power to influence decisions that could adversely affect their professional position and functioning. Lapses and insufficiencies in their professional performance could also be used as an excuse for vindictive targeting by the powers-that-be, hence health functionaries had to be mindful of maintaining good relations with influential people. Hence, service provision reflected the power dynamics of the village. Krishna's uncle*** *was of the opinion that all the people in the village ought to get the available services without any kind of discrimination, based only on their need and the nature of their health problem.*

He emphasized the *delivery of available services equally to all without any discrimination and* ***was of the opinion that the PHC staff ought to not be influenced or allow the power politics of village to affect their practice***. ***He felt that the*** *d****octors at government institutions did not have patience and lacked both manuski and the necessary skills for interacting with patients and attendants***. *He was traced their apathy towards performance to the assured fixed salaries every month, that left them with no motivation to* ***make the effort to treat patients. He described them as using referrals to higher centres as a means to avoid being responsible for their patients; trying to get rid of them, sending them away out of their sphere of work or at-least out of their institution.***

If they admitted patients or kept them under observation, doctor too would have to wait or stay back at the institution till the patient improved or was out of danger. They did not want to be held at the institution, just work for the fixed hours they were mandated to be there, oversee work, see to all tasks being taken care of and leave as soon as possible. *The doctor's reluctance to be present at the institution could* be a defensive practice or due to lack of skills, or frustrations caused by insufficient supplies, equipment or infrastructure to treat patients properly or ensure cure or could just be a lack of interest in making the effort to treat patients; or a combination of all.

4.2.2 Private sector

Block level

The issues related to inadequacies of infrastructure, services, human resources, technical resources, consumables and culture of medical practice was a problem not only of public sector hospitals but was also observed in private sector as well. As one goes down the levels of health system these inadequacies (in comparison with what was prescribed for that level and expected by the community from that level) were more prominent and affected the people more, pushing them out of their comfort zone to seek essential care to relieve suffering. *After trying out treatment at PHC her family had taken Mayabai to some private practitioners in Kandhar. The private hospitals and practitioners consulted included Dr. Gudwane a BAMS doctor, Dr. Ghardive a MBBS doctor and Dr. Khure MBBS, DGO. All of them had given her some injectable medicine during the OPD timings and some oral medicines to be taken for 10-15 days. She had completed the prescribed course of medicines received from all the doctors but none had been*

effective in stopping her problem. They had spent on an average INR 200-500 at each visit for the treatment at Kandhar. Despite spending so much money there was little improvement in her condition. None of the doctors had diagnosed her condition or advised them to seek care from an institution at a higher level. While reflecting on the experience with private clinics and hospitals in Kandhar, Bishan said that none of them had USG facilities so they could not diagnose her problem or offer relief. Bishan thought ***that lack of availability of USG was what made doctors (private GPs and government hospitals) in Kandhar incapable of diagnosing and treating her condition.***

Most of the private hospitals provided services related to one or two specialties depending on the specialization of the doctor couples or individual doctor. There were some private hospitals run by a group of doctors with experts from four-five specializations. The permutations and combinations of specializations were dependent on their social and business links, unrelated to medical or epidemiological or public health logic. Thus, the range of specialized services provided offered at a hospital had many limitations. Most of these hospitals depended on other diagnostic centres and laboratories for diagnostic services. Availability of specialists and services in the district town of Nanded made it possible to access all relevant services but not without difficulty. However, such a situation remained a very distant dream, even for private hospitals at the block town. The availability of specialty services at the block town had many hurdles. ***Sulekha's delivery had ended with complications for the baby. Delivered by caesarean section, the neonate had suffered meconium aspiration and needed hospitalized care under a paediatrician. The doctors told them that the baby needed to be kept in a glass cubicle (incubator). This facility was not available at Dr. Adhav's hospital****, since he was an Ayurvedic doctor by training. The only place with the facility available in the town was Dr. Khure's hospital. Nayan and his family believed that Dr. khure had deliberately harmed the baby in order to settle the scores from a past conflict. When the family was told about the meconium aspiration pneumonia and the condition of the baby, they attributed it to the actions of Dr. Khure (Dr. Khure as the only fellow gynaecologist from the town had assisted Dr. Adhav,during the C-section). Dr. Adhav'sadvice to get the baby admitted at Dr. Khure's hospital was not acceptable to Narayan and his family. He refused to get the baby admitted at Dr. Khure's Hospital, but that late at night they had no option but to keep the infant admitted there. At Dr. Adhav's and his relatives' request he kept the baby admitted there for the night where baby was kept in the*

separate room meant for babies, where all the babies were kept in incubators. No one was allowed to stay in that room. ***The mother was still receiving post-operative care at Dr. Adhav's hospital while the baby was receiving neonatal care at Dr. Khure's Hospital.*** *The next morning at Dr. Adhav's advice, they decided to take the baby to Dr. Panwar, in the adjacent town of Loha,* ***15 km from Kandhar but well-connected to the block by road. For a few days the baby and mother were apart accompanied by two sets of attendants, also facing problems of stay,*** *, sleeping in the corridors and eating from street food joints.*

District town

At the district town a wide range of services and specialists are available, but are scattered all over, in different private hospitals. So even when people visit these private hospitals, for specialty care, only a limited range of services are available. Patients have to go to different diagnostic centres for the necessary services even during hospitalization. The government hospital offers many of these services under one roof but has its own institutional mechanisms of specific working days and timings for each specialty service that make services inaccessible to people travelling to the hospital from faraway places. Private hospitals on the other hand have flexible institutional processes and make accessing services convenient. *Many of the respondents were of the opinion that if such services are available under one roof or in one institution even in private sector, it would save time, money and efforts of using those scattered services.*

Trust hospitals

Caught between the inaccessible and inconvenient government hospital on the one hand and expensive even unaffordable private hospitals on the other side, some patients from the village explored the option of not-for-profit trust hospitals. These not-for-profit trust hospitals were also beyond the economic reach of many, but offered some services at lower rates as compared to those prevalent in private hospitals. Care-seeking experience at these hospitals came with their own set of problems. Talking about Shambhu's experience at Tayar hospital, the not-for-profit trust hospital that he had approached, he said that most ***the doctors were visiting consultants****. Though their instructions for treatment were followed, any changes required in regimen or medication were affected by the fact that the consultants were few in number and did not visit on regular basis****.*** *Even so, the hospital was suitable for poor people since it provided treatment at*

minimal costs and unlike other places it did not try to get rid of the patient before they experienced improvement of cured.

In summary, the availability of a wide range of functional and responsive services at an easily accessible distance, not far from their place of residence was considered a crucial issue by community members. They recognized that it was not possible to provide all services at the level of the village but the respondents and community members articulated very clearly that the district town was too far, and its distance made the utilization of such services inconvenient and costly. Therefore, they preferred the block level for the provision of as wide a range of services as possible, so the trips to the district town could be avoided.

People from the village pointed out various inadequacies and the poor attitudes of health care providers from government Hospitals at block town and district levels. However, people were aware that the poor work culture and attitudes of health workers of government hospital also has some reasons. *Nayan commented on long working hours for doctors and health professionals.* ***He told that health professionals, doctors specifically are made to work for long duration of time. Long working hours consisting of clinical, monitoring and supervision activities along with administrative work was responsible for inappropriate behaviour and loose temper in doctors and neglect of the patient care. He further suggested reducing the working hours for doctors from 8 hours to 6 hours and increasing the necessary number of doctors.***

4.3 Institutional mechanisms for safe and effective services

In addition to institutional level structural / input-related factors as discussed above, some institutional level processes were also highlighted as a significant part of their care-seeking experience. The division between institutional processes and institutional input factors is for the sake of convenience of discussion here and to make clear the site and nature of problem in quality or the areas of strength in quality. The division is not a water-tight compartmentalization and will see some overlaps also. Factors like the institutional culture of medical practice are difficult to categorize, for they appear at first as more a part of the institutional process but institutional culture is also a given, which health workers enter and have to work with- so here it is treated as a structural aspect of the institution. Institutional inputs and processes tend to shape

each other as well viz. the availability of sufficient / inadequate human resources, material resources and financial resources shape institutional processes and practices.

4.3.1 Public sector

Qualified and adequate human resources are essential for providing quality health care services. It is also important that health workers have necessary skills and the right attitudes for providing health care, they affect the nature and extent service delivery and avoidance on their part. Avoidance or refusal of simple treatment interventions by doctors in government hospitals, reported by many community members, had over time led people to believe that these institutions did not function or provide the required medical care. *For instance, the doctor at the PHC had referred Ranpat, to Kandhar for the removal of sutures from a wound. Ranpat had to go to Kandhar to get the it done and even a simple removal of sutures was not done by the medical officer at the PHC.* There were other community members who had similar stories. The removal of sutures, post-surgery could be done by any doctor according to the surgeons at the district town, but the PHC medical officers refused to perform suture removals and patients were forced to travel to secondary or tertiary institutions for a procedure as simple as that. The possible reason for reluctance in suture removal among the medical officers could be their lack of information on the nature and type of surgery or the possibility of infection due to unsterilized instruments at the PHC and sterilization of instruments would mean additional work at the PHC.

Over time, community members had realized that the skills and knowledge of doctors at the PHC level were also inadequate. Coupled with inadequate diagnostic infrastructure, the required consumables and medicines. The lack of skill and knowledge among doctors affects service delivery in critical ways. Nanak More, took his young niece to the PHC and found the *doctor* ***PHC ill-equipped and too in confident to investigate and treat the baby who was having a seizure.*** *He could not alleviate their anxieties about the causes and condition of the baby which to the family was a serious one. Their perception of him as incompetent was only strengthened further when he asked them to transfer the baby immediately to Kandhar. All he gave as treatment was a* ***regular syrup, while the family had expected a different treatment regimen for an ailment that appeared serious to them. Thus, they concluded that PHC and the doctor were not equipped (with knowledge, skill, medication and equipment) to handle seizures in children.***

Besides their scepticism regarding the skills and competence of health workers, community members also doubted the attitude they brought to their practice. Their readiness to deflect patients from their institution to another through referrals or refusal to admit was perceived by community members as a sign of their unwillingness to act responsibly towards the latter. Referral, though an established institutional practice had come to be questioned by people and viewed as an act to evade institutional responsibility. *The 'trend' among government doctors and health workers to avoid responsibility of patients was among the reasons Nayan gave for not seeking care in government hospitals. Drawing on his daughter's and other women's pregnancy and child birth experiences at the PHC he said 'If there is a case of delivery in the village then one family member goes to the PHC and informs the sister about the case. (It was widely known that doctors won't conduct delivery, the ANC was also provided by the ANM and doctor was usually not available beyond fixed hours, therefore they approached the health worker who was available- the ANM.) They ask her whether they should bring the patient (the woman in labour) to the PHC, and the sister will tell them that she will come to home to see the patient. Sister will visit the pregnant woman at home and examine the patient, then inform them that the woman will need more time. After some time, another relative will go and inform the sister about her condition.* ***Sister will return to visit her after some time and after examining her, she will say again that she will need some more time, if they want to wait, they can or else if they feel that the pain is too much then they can go to Kandhar. With a non-committal answer such as this and with a patient in pain, the family will then decide to take her to Kandhar.' He said that if the sister at the PHC took the patient to the PHC examined her there, gave her some medicines, and reassured them, and made a sincere effort to attend to the delivery then they would appreciate the services provided. According to him the ANM's*** **reluctance to get the patient admitted was because, the latter would need her to work and would be her responsibility once admitted. In concluded that the staff at the PHC avoided measures that would make them an 'official patient' to avoid answerability. They did their best to keep approaching patients at bay and if someone was admitted they saw to it that they went out of the institution as soon as possible.**

Once patient was taken to ***Kandhar, to the government hospital (RH), they generally admitted them immediately and prime the relatives to be prepared to take the patient to Nanded on referral. In most instances they would refer the patient after*** *admitting them for a few hours.*

His daughter had been admitted for almost eight hours. If the delivery did not take place within that time, the doctors referred the patient to the district hospital. ***Most patients referred from the RH would have normal deliveries at the district hospital, which raised the question whether the referral was justified. There were many examples of patients having delivered normally in private vehicles like jeeps and auto rickshaws enroute to the institution they had been referred to. The deliveries had been attended by the accompanying women. These referrals had been from the PHC to the RH and from the RH to the district hospitals. No woman deserved such treatment; having to deliver in the middle of nowhere, on the road, in some auto rickshaw or jeep attended by an unqualified and inexperienced relative. These deliveries had taken place despite them visiting qualified doctors at government-run health institutions.*** This phenomenon was evidence of **unnecessary or irrational referrals and that in effect were ways of abandoning patients and putting them at greater risk.**

In a multi-layered health system with interconnected institutions or even in the private health care institutions, when the patient moves or is referred from one level to another, the assumption is that the problem-appropriate intervention was unavailable hence the referral institution would offer something more advanced/different from what the referring institution could make available. If one ends up receiving the same set of medical interventions with little demonstrable difference at the institution one is referred to, then the effort feels futile community members. Community members were referred from the PHC- an institution that was being run by a single medical officer to the RH where too only one doctor was available on duty, the only advantage being the doctor was available round the clock. The RH had a larger infrastructure with in-patient facilities but usually had the same set of medicines as prescribed at the PHC. *Community members* ***assumed that if the ailment did not respond to the medicines provided at the government-run PHC then it was unlikely to respond to the same set of medicines provided at the government institution in Kandhar, hence they preferred to go directly to the private clinic.*** There also was a lack of coordination among referring and referral institutions that seemed to share no dialogue and were seen contradicting each other.

Nayan and Ranpat preferred a private clinic at Kandhar over the government RH. This was based on their past experiences when the doctors at RH Kandhar had shouted at them for approaching the RH instead of the PHC at Panshevadi. According to the doctors, the same

ailment should have been tackled at the PHC. Doctors at the RH had told them that PHC was equivalent to RH Kandhar, and in many aspects like medicines and facilities, even better as compared to the RH. ***They had been sent back often, without any treatment from the RH. The RH would offer treatment only for*** medico-legal cases and for some emergencies like snake bite, accident, injury, delivery etc. The **unfair scolding from doctors at the RH had resulted in them avoiding the hospital.** These responses from the doctors at the RH raised their expectations of the PHC and led to an unnecessary comparison of PHC with the RH, with people blaming the PHC for being inefficient, unsatisfactory and having a limited range of medicines and services.

As far as they were concerned the experience at the RH had told them that, the institution only addressed and provided treatment for medico-legal cases along with first aid for some emergencies like snake bite, accident, injury, etc. Barring its services for these conditions and the round-the-clock availability of a doctor, the RH did not come across as an institution suitable for accessing a 'higher level' of care**.**

The community prioritized concerns about OPD care and hospitalization care differently. The OPD care experience with institutions was usually lasted a few hours, of which the interaction with doctors was usually a few minutes. The hospitalization experience entails longer durations of stay and interaction between patients, attendants and doctors bringing out dimensions of quality in health care journeys, that may not otherwise be apparent in OPD care. Institutions such as the RH and those at still higher levels, given their nature of services, have health workers and doctors working in 8 or 12-hours shifts. The change in health workers was also a source of concern for some. *Narayan sharing his experience in the hospital said that* ***change in the duty of doctor*** *triggered* ***insecurities and anxieties in patients. The patients may not be sure whether there would be a replacement, or whether the replacing doctor would be responsive to them or whether the patients and their relatives would have to start from scratch or follow a new set of instructions and make other adjustments in accordance with the new doctor. He believed that the process of changing duties of doctors and other health workers like the sisters could lead to neglect of some aspects of treatment and patient care****.*

At institutions like medical college and district hospitals shifts change daily and doctors too depending on the days of the week. Even on a single shift, there is a greater number of doctors

and it is not always possible that the patient will be seen by same doctor during subsequent visits. Tertiary care hospitals often require repeat visits given the nature of the illnesses they treat and the institutional mechanisms they have. *On asking Keshram his opinion about his overall experience of* ***the government hospital he said that, that since the doctors had left early from their duty, he could not consult them on his first visit and had to return another day, travelling seventy kilometres one way****. He visited the medical college hospital again and was referred to the surgeon from the skin OPD. At the advice of the doctors, he got his FNAC done, that required two more visits before visiting the surgery OPD where he was seen by a new doctor. He explained that it became* ***difficult for the patient if he was seen by a new doctor every time. It created apprehension and confusion as to whether the new doctor would know about the condition or whether one would have to go over it all over again. The rapport developed with the earlier doctor was rendered useless, and the patient was constantly negotiation a new relationship with a new doctor, that undermined his confidence****.* Keshram's entire treatment experience discussed in the previous chapter showed how it involved multiple visits to the government medical college and district hospital and at each visit he had to consult a new doctor.

The problem with new doctors gets complicated further when they invest very little time in discussing the nature of the illness, taking the patient's history and performing the clinical examination. The patients were quick to recognize the lack of sincerity in their approach and work. *None of the doctors Keshrammet in his subsequent visits, or even observed with other patients, invested enough time in making enquiries and examining the patient.* ***Most doctors were in a hurry to be done with or to get rid of the patients. The overall work culture was poor and this poverty of work culture existed among all types of workers in the hospital and the health sector. Keshram attributed the phenomenon to the lack of sincerity in the doctor's work. He saw doctors at the head of the health care delivery system and, if the boss or head was insincere then everybody working under him turned insincere and the overall work culture got affected.*** *If the doctors were on time and working efficiently then everybody in hospital would work properly too.* ***If the boss or supervisory authority was absent then everybody would become bosses in themselves and the whole situation would turn unruly, affecting the work ethos and culture of the institution as a whole.*** *Recollecting his experience in the lift, and having observed* ***several patients being shouted at different places by either the doctors, or***

nurses or by other supporting staff. He said that it was very important that the hospital staff behaved in a humane manner with patients.

Insensitive attitudes of health care providers were reported by many community members. The insensitivity can come across as indifference towards patients and their suffering. This indifference and lack of concern get reflected in the many examples of the doctors' refusal to care, their avoidance of the patient and the irrational referrals. People have learned to live with the indifference of health care workers towards patients. However, many times the insensitivity among healthcare workers coupled with their power positions especially over vulnerable patients translates into insulting comments and behaviours. *Ujalasaid that she was very sensitive by nature. If somebody insulted or made demeaning remarks or behaved inappropriately with her, she would get tense and lose her temper.* ***The chances of getting shouted at, scolded, insulted or looked down upon were very high at the hands ofa doctor, a nurse and other paramedical workers at the government hospital. Ujala avoided this institution to avoid the insensitive, inhuman and undignified treatment they meted out to patients.*** *In her words, 'After all the government hospital is just going to give a few tablets and not some amrut (elixir of life) or gold, then why get insulted for those if similar ones were available at private clinics on paying some money'.*

The organization of different departments and their patient-related services in the medical college hospital was enough to throw off uneducated patients or those from rural areas, women and people with disabilities. They had to go from one building to the other searching for departments in different buildings and corners of the hospital premises. Poorly maintained, dirty, dark passages were confusing to navigate while the complex infrastructure and organization of services added another layer to the bureaucratic complexities of obtaining signatures and permissions from concerned authorizes, keeping track of different timings and reaching the different sites for paying user fees, giving, samples and collecting reports from different diagnostic services like microbiology, pathology, radiology etc. within each department. All these bureaucratic processes within hospitals were time consuming, inconvenient and tiring. Ujala further added that *the* ***complex and confusing treatment process involved running between different departments in the big hospital and that posed an additional problem over and above the behaviour of the health workers. The timings of the hospital were such that one***

rarely completed the treatment process in one visit, consuming more time and money both of the, patients and attendants. *She had visited Nanded only once, for her problem and it was little surprise that they chose the private nursing home, they had heard of, for her subsequent treatment.* Time consuming institutional processes necessitated multiple visits to complete the treatment process, and made treatment a very difficult endeavour for people in villages at a great distance from the district town. The previous chapter had discussed the multiple visits that Keshram's care-seeking from the government medical college and district hospital Nanded entailed. The multiple visits were possible in his case because he was a middle-class, young adult, male pursuing his undergraduate studies in pharmacy and was the son of a government health worker, that allowed him both means and familiarity enough to make that effort. The effort and resources that care from secondary and tertiary government institutions demanded could easily translate into no care especially for elderly and women, especially in poor families.

The multi-speciality hospital with different diagnostic services was seen as strength for providing comprehensive treatment by some of the community members. Multiple evaluations of patients by different levels of doctors were viewed as contributing to better management of illness and complete cure and care of illness, especially major illnesses or complex diseases. According to Bishan, The presence of multiple doctors with different levels of expertise in a team, helped avoid mistakes and increased the likelihood of appropriate care. *Mayabaihad been suffering from nausea, burning sensation and pain in abdomen with intermittent bouts of vomiting, diarrhoea and mouth ulcers for a long time. She had sought treatment on multiple occasions from the PHC and from different GPs in Kandhar. She had also gone to Dr. Bawadekars's private hospital where she had undergone USG abdomen, at Dr. Bawadekar's advice. The USG had revealed gall stones for the removal of which the doctor advised surgery as early as possible to relive suffering. The cost of operation as suggested by the doctor was around INR 20,000. He suggested that if they could not perform the operation at his hospital then they might have to go to Mumbai or Hyderabad for the same. Given how expensive the surgery was turning out to be, her family decided to go to the government medical college hospital. At the district hospital they* ***got the paper of the surgery OPD*** *and were seen by Dr. Ghosikar. They also showed him Mayabai's previous papers, including the USG reports. By this time Mayabai had become very weak, and the USG on admission to* ***the hospital confirmed the gall stones****. The* ***investigations for anaesthesia fitness revealed that she had some problem in her heart because of which she***

could not be operated upon. Doctors in the hospital after thorough examination prescribed her to some medicines from the hospital and asked her to return after a month, suggesting that she could undergo the operation if her condition was better the next time. *Thus, different specialty services were used at the medical college hospital to assess health problems she had and an effort was made to take care of those ailments as well. Bishan, her husband then requested the doctors to do something about the burning pain in her abdomen, loose motions, and mouth ulcers because those were her pressing concerns and taking her home without treating those conditions would just amount to keeping her in pain and suffering.* ***He told them that she could not eat properly; was weak and feeling giddy often due to the weakness. Doctors subjected her to another set of procedures, from her account it appeared, most likely to be endoscopy. She was given treatment in the hospital for a few more days and discharged after almost 12 days of hospitalization****. She could eat, her burning pain had significantly reduced, her giddiness had subsided and she was feeling much better, after treatment during hospitalization. With much improvement in her condition, after discharge, she completed a month of medical treatment at home. She was taken to the district hospital after completing the prescribed treatment and was admitted for surgery. After completing the necessary tests, she was operated upon and recovered from her illness and at the time of the interview expressed her satisfaction with the care that she had received at the government medical college hospital.* Thus, institutional infrastructure, diverse services and human resources as different teams of health care providers contributed to providing appropriate care. Mayabai and her family believed that if they had gone to a private hospital then they would have only had surgery and not made the effort to provide comprehensive care.

Teams of health care providers with different kinds and levels of expertise like doctors, nurses, physiotherapists etc. also enabled checks and balances on each other's actions, helped avoid mistakes and provided appropriate care. Institutional mechanisms like supervision, monitoring and evaluation of work by senior professionals help in improving work culture. ***Asaya during her hospitalization at the district hospital seemed impressed with the fact that one day a lady at a senior level, a boss had come in to the ward and collected the papers from all the beds and examined them. Later she had also enquired of all the patients about their condition.*** *This* ***mechanism of monitoring and evaluation present in the government hospital, that tracked the***

treatment process was contributed to her trust in the hospital's activities and in building her opinion about the institution.

Overcrowding in government hospitals with long queues in the OPD and IPD was another cause of concern pointed to by most of the respondents. Some added that a high number of patients catered to by a small number of doctors and nurses, that too practitioners with poor attitudes, led to negligence or lack of personalized attention to the patients in both OPDs and IPDs. This concern was only exacerbated in case of hospitalized patients with serious illnesses. There was a possibility of mismatch between expected, required and actual attention received by patients**.** ***Asaya added there was usually a demand by some patients for constant personalized attention and care. The expectation that a nurse would give the majority of her time to one patient was unreasonable and impossible since there were many patients and each was equally important to her, even though for relatives and attendants their patient would be their sole concern.*** This mismatch was one of the important reasons for dissatisfaction with services at the government hospital and for people to show a preference for private hospitals. Private hospitals had others strengths and weaknesses owing to their institutional processes and mechanisms, and are discussed in the segment that follows.

4.3.2 Private sector

Private hospitals were used for their OPDs, diagnostic and hospitalization services including surgical care, depending on the needs and requirements of patients and their ability to afford them. Private hospitals evolved over a period of time by providing services that were not available in the government sector institutions or by providing services in a manner that was more convenient and attractive to patients. Unfulfilled expectations about health care services have been important grounds for people to explore services in the private sector, which the latter caters to. It was observed that the current competition among private hospitals and providers was contributing to both fulfilling existing expectations as well as creating new ones among people. *The* ***advantage that private hospitals offered according to Keshram was that they provided services immediately. The queues and waiting times were both much shorter. Doctors were not rude and there was some room for patient to inquire about the nature of their illness and discuss possible options for treatment options.*** This room though might not fully materialize in reality, given the asymmetry of knowledge and the power dynamics between the doctor and the

patients is evident from the discussion with many community members who had sought care from private hospitals.

Seeking care from private hospitals for its advantages sounds logical but the cost of that care makes those services inaccessible for many, especially when it came to surgical care or care for problems requiring hospitalization. The preference and use of private hospital services was guided by many considerations like costs, nature of illness, status, roles and responsibilities of the person needing care, accessibility, availability of alternative services in the government sector health care institutions. *When it came to emergencies and precious pregnancies or a first delivery, private hospitals were preferred, specifically by economically well-off families because they could avail personalized services in these institutions. Sometimes it effectively proved economical to seek treatment at a private hospital because they responded promptly* ***with high end medicines, reducing the total duration of illness. The ready response also cut down on indirect costs as it reduced the total cost on traveling, of repeated visits trying out different treatment and medication regimen. , It also reduced the length of the illness since immediate treatment with better medicines (the chances of getting both were higher in private institutions) brought faster relief. Reduced durations of illness also saved work days and the wages that may have otherwise been lost to sickness.*** *Thus,* ***sometimes the total cost of treatment at private clinics, for conditions not requiring admission, was lower especially with their lower, indirect costs. This was possible due to their institutional processes which made efficient use of necessary services without bureaucratic processes.***

The promptness of service delivery and the shorter durations of treatment to relieve suffering were often quoted as advantages and became grounds for choosing private hospitals. Time was a very important consideration for people from villages far from the location of health care facilities especially in district towns. Delay in service delivery and longer durations of treatment escalated the direct and indirect costs involved.

Therefore, for illnesses requiring OPD care they wanted to complete as much of the care process as possible in a single visit to the district town, if they were lucky in one day. Once travel time using public transport with its fixed and infrequent service was excluded, they had very few hours at their disposal to actually access care. Given the inflexibility in time, any delay could mean an additional trip and another day lost in the care-process. So, they preferred institutions

which organized consultation, diagnostic testing (if required), and treatment in a manner that could be finished in a few hours within a working day.

Hospitalization at the district town often meant that family members whose availability affected all economic and social activities would need to be away. Thus, for illnesses requiring hospitalization the preference was for institutions that start the required treatment promptly and finished as soon as possible. If it was an emergency requiring medical intervention that could be completed in a short duration, then the family preferred it be done quickly so they could use the same private transport vehicle that they had hired for getting the patient to the facility for their return as well. If hospitalization was required then the expectation was that of quick relief from symptoms and discharge; even when the services were free, since able-bodied adults and parents being away as attendants at the hospital, affected the entire family especially if there were small children or elderly members. . The attendants of the patients additionally had to depend on food bought from the market, and sleep in the hospital verandah and corridor. All these difficulties made a short duration of stay at the hospital an important criterion for choosing a facility.

While commenting on the comparison between public and private facilities, Kavitasaid that her experience of getting care in a public hospital had been good. After hearing experiences from other villagers, she though that her personal experience could also have been due to her family's connections with the chief medical officer of the RH. She said that if she had to take a patient to the hospital then she would choose the public sector only for minor and less serious illnesses and pick a private hospital for serious illnesses. ***The reason for such a choice was based on other's experiences that she had heard about. She believed that treatment was generally not started promptly and done efficiently in public sector institutions. They involved a lot of waiting time, long queues and bureaucratic procedures. Patients were attended to in public hospitals immediately only if in a life threatening emergency.*** *No one wanted that fate so she would prefer to go to private and get treated. Hiralal, her husband, added that the neglect of the patient, carelessness along with delay in service provisioning was a very common feature of services in public hospitals. He said that though it was possible to obtain most of the services at government hospitals but these services were not available on time.* ***Overtime, the people's overall belief about the public hospital services had become negative. Private hospitals provided services on time and with some care in their attitude to be able to earn money. They***

understood the existing situation in the public hospital in terms of the overall poor work culture among doctors and hospital staff; the fixed and secure salary that did not get affected by their lack of performance; the absence of both incentives and punitive action and the lack of effective monitoring and evaluation of the performance of the health workers and doctors. Thus, the lack of discipline and commitment to work amongst the health workers in the public sector hospitals was considered the reason for delays in service provisioning, neglectful behaviour and careless services.

4.3.4 Unnecessary interventions

Given the emphasis on prompt treatment in the community's narratives, an attempt was made to enquire more about the services delivered by the private sector. Members were asked to comment on the rationality and appropriateness of care in the private sector. *When Kavita was asked to compare the private and public sectors on the possibilities of getting rational or appropriate treatment she said that she did not see much difference.* ***When asked in terms of the un-necessary investigations, medicines, interventions and operations, she said that respected medical professionals would not be doing so, showing her trust and faith on the medical professionals.*** Lay persons have limited means to understand the nuances of the highly technical field of medicine. Hence their involvement in the decision-making process during treatment is limited. The scope and avenues for verifying the decisions made by the medical professional are very limited or are in fact are non-existent. **However even so, people are able to decipher the possibility of unnecessary interventions or other malpractices. For instance, in the discussion *Kavita recollected her experience at Dr.Bawalekar's, in his private hospital and said that he might have performed a caesarean section upon her had she stayed back in that private hospital, but since she had gone to the RH Loha she has been able to have a normal delivery.***

The phenomenon of irrational care or inappropriate treatment, diagnostic tests, medical and surgical intervention at private hospitals has become public knowledge. Many respondents voiced concerns over it. ***Ranpat suggested that the un-necessary and even wrong treatment, were a means to extract money in the private sector. They informed that they still went to the private sector because government. health institutions did not give treatment. If and when they did, it was not timely or humane. Given** a **choice between no treatment or unsatisfactory and***

delayed treatment dispensed harshly, on the one hand, and on the other side was treatment with a possibility of irrational or un-necessary prescriptions at a higher cost, they would opt for the latter. Only of the cost of care was too high did they explore care in a government hospital. Community members wished and expected that government hospitals provided *timely treatment.*

Community members based on their care seeking experience reflected on the pros and cons of different institutional mechanisms. Some of them also delved into the structural and behavioural reasons behind the observed pros and cons of institutional processes. ***Kavita and her family*** *attributed* ***the inappropriate behaviour, shouting at patient and their relatives, disinterest, neglect and the careless attitude of doctors and other health workers to factors like poor work culture, lack of incentives and punitive action based on performance, fixed and secure salary and the lack of monitoring and supervision.*** *When asked about the differential workloads in public and private institutes they admitted that there was a huge difference in workload in terms of the amount and nature of work, the kinds of patients and conditions catered to. T****he high work load at the public hospital was considered, one of the key factors behind the unfriendly and short-tempered behaviour of the hospital staff. Heavy case load and the constant rush at the government hospitals were also implicated in the same.***

4.3.5 Cleanliness and hygienic environment

The popular impression was that services offered at government hospitals were undesirable since the institutions were very dirty and poorly maintained. To understand the community's concerns regarding institutional mechanisms put in place for keeping the hospital clean, some enquiries were made on sanitation and cleanliness in hospitals. This had been discussed in some detail in a subsequent chapter on support services. However, it was observed that very few respondents highlighted cleanliness in the hospitals as an important consideration for evaluating their experience of care-seeking. ***When asked specifically about the cleanliness in private hospitals and its importance in their preference for a private hospital, Sulekha's family said rather clearly that it was not their primary concern. They said that they were after all not going to stay there for long, it was just temporary and the hospital cannot be as clean as their home anyway. They reaffirmed that they preferred private hospitals because they offered them quick care, along with visible effort by the doctor to secure the patients relief from their suffering.***

4.4 Summary

Table 4.1 Desirable and Un-Desirable Aspects of Experience and Expectation from Institutional Structures and Processes

Desirable aspects of experience and expectation from health services	Undesirable aspects of experience and expectation from health services
System structure of health services • Government. hospital offers many of these services under one roof • ***Increasing the necessary number of doctors- to ensure humane behaviour and responsible conduct from doctor*** • Availability of wide range of functional and responsive services as close to them as possible • Level of block town was preferred as level providing as wide range of services as possible	• Travel long distance • Pay more consultation fee, • Transportation and other for logistical expenditure in addition to medicines and consumables. • Unavailability of those services in the towns closer to them pushes them to far away cities, making services inconvenient and expensive. • ***Only one medical officer posted at PHC who does not even stay there*** • ***PHC is not seen as reliable source of treatment*** • Limited services available from PHC • Unavailability of doctor at PHC makes emergency services and expert opinion very expensive with transportation cost of travel to a distant place • *Inaccessible and inconvenient government hospital* • *Unaffordable/costly private hospitals* • Lack of co-ordination among institutions, referring and referral institutions seemed to be in no dialogue or were contradicting each other.
Institutional features – inputs • Availability of clinical infrastructure, diagnostic services, human resources and specialists, emergency services etc. and • Many medicines were provided from the hospital side during their hospitalization and that saved their significant amount of money. • ***Doctor who is residing in the village makes significant difference in the accessibility, the behaviour and approach of the doctor***	• Poor infrastructure, inadequate number of doctors, nurses, support human resources; lack of availability of many medicines and other consumables etc. • Lack of various services like diagnostic services, emergency medical services, indoor services, specialist services, surgical services etc. • The lack of availability of residing medical officers in PHC • Inadequate diagnostic infrastructure and required consumables and medicines affects the services

• Round the clock doctor availability of doctors • Multi-speciality hospital with different diagnostic services was seen as strength in providing comprehensive treatment	• Unmindful infrastructure and organization of different facilities within hospital premise posed additional challenge.
<u>Institutional features – processes</u> • Rational services, comprehensive services, safe and effective care and institutional culture. • Institutional processes flexible and make services convenient. • ***Complete the treatment procedure and go back home from Nanded in government. district hospital in one day.*** • Multiple evaluations of patients by different levels of doctors was considered as contributing to better management of illness • Presence of multiple doctors in a team from different levels of expertise avoids mistakes and increases likelihood of appropriate care • Having teams of health care providers with different levels of expertise and professionals • Institutional mechanism like supervision, monitoring and evaluation of work by senior professional helps improving work culture. • ***Provided services immediately. Waiting line and queues are small.*** • ***Efficient use of necessary resources without bureaucratic processes*** • Services as per convenience of patients • The flexible timings; no waiting time; no bureaucratic procedures like paying fee at one place taking paper then consulting a doctor, then getting appointment for diagnostic tests, separate queues for receiving medicine etc. • ***Complete the whole procedures in one day***	• Impossible for the community members to demand accountability from medical officer- range of tasks assigned to him which require him to go out of PHC building. • Limited ranges of services are available. Patients have to go to different diagnostic centres for the necessary services during hospitalization. • Institutional mechanism of specific working days for certain specialty services, timings etc. which make eve the available services inaccessible to people travelling from faraway places. • ***Numbers of visits of these consultants were few and not regular. So changes if needed during the course of treatment would get affected.*** • Poor work culture and attitudes of health workers of government hospital • Doubtful referrals and • Questionable behaviour of responsibility of the institution. • **Unnecessary or irrational referral and inappropriate ways of referral where patient is left attended by unqualified person in some unequipped vehicle.** • ***Insecurities and anxieties when there is change in the duty of doctor.*** • ***They are not sure about when will next doctor come, when next doctor comes then the issue is when he will attend the patient, and the fact that as this doctor is new, patient and the relatives will have to undergo new cycle of doctor patient interaction and adjustments.*** • *It becomes* ***difficult for the patient if every time a new doctor sees them.***

	This creates confusion as to whether he will know about the condition or whether one has to go all over it again. The rapport developed with earlier doctor is of no use, so patient is constantly in a new relationship with new doctor. This undermines the patients' confidence • ***Poor working culture was among all types of workers*** • ***Complex and confusing treatment process involving running between different departments in the big hospital.*** • ***The timings of the hospital become additional constraint for the people coming far away rural places. One cannot complete treatment process in one visit so it becomes resource consuming in terms of time, money, attendants needed, and time of the attendants needed.*** • Time consuming institutional processes • ***Long waiting time, long queues and bureaucratic procedure*** • ***Services are not provided on time and with caring attitude.*** • ***Lack of discipline and lack of commitment to work amongst the health workers*** • ***Delay in service provisioning, neglect of patient and careless services*** • ***Lot of running from one room to another deciphering the maze of different departments in different buildings.*** • ***OPD paper distribution time gets over. It also involves standing in long queues everywhere for taking signatures of doctors, or appointments, for investigations, for medicines and procedures etc.*** • ***Needed someone to stay with patient constantly and his wife was staying with him.***
<u>Attributes and features of provider</u>	• Reluctance or (incapability) of doctor

• Skills and attitudes of the available human resources • ***Proportion of doctors with manuski was more in earlier days*** • ***Doctor who is residing in the village makes significant difference in the accessibility, the behaviour and approach of the doctor*** • ***Take responsibility of the patient while treating. The responsible behaviour of the doctor gives confidence to the patient*** • *Provision of equal access and delivery of available services to all without any discrimination were stressed by him.* • Attitude and skill of health care workers • ***some kind assurance*** • ***sincere efforts, puts in some visible efforts*** • ***Doctors are not rude and there is scope for having a conversation where patient can inquire about the nature of illness and treatment options***	in treating routine illness • ***Doctors are not taking responsibility*** • ***PHC staff should not take part, imbibe and practice the power politics of village.*** • ***Doctors at government. institutions don't have patience and manusaki i.e. humane nature and skills to interact*** • ***Government. doctors don't want to take responsibility so all the time they want to send the patient away at higher level, out of their jurisdiction or at-least out of their institution.*** • ***They don't really take efforts to treat patients.*** • Avoidance or refusal of simple treatment interventions from doctors • Lack of skills and knowledge • ***Doctor was not equipped (knowledge, skill, medicine and equipments wise) to handle the condition*** • Rude and insulting comments and behaviours. • ***Getting shouted at, scolded, insulted or looked down upon*** • ***Insensitive inhuman and undignified treatment*** • The insensitivity comes across as indifference towards patients and their suffering. This indifference and lack of concern • Poor attitudes, leads to negligence or lack of personalized attention to the patient in OPD or IPD.
<u>Medical/ clinical care components</u> • ***Prompt treatment with high end medicines reduces the total duration of illness. It also cuts down much of the indirect costs as it reduces total cost on traveling doing repeated visits trying out different sets of medicines, it reduces total duration of illness*** • ***Faster relief cutting down total duration of illness thus cutting down the wages lost due to illness.***	• Little time to discuss the nature of illness, history taking and clinical examination. • The lack of sincerity in their approach • ***In hurry to get rid of the patients as quickly as possible*** • Refusal or avoidance of care or in unnecessary referrals. • Mismatch between expected attention, required attention and actual attention receive by the patient from doctors and

• ***Some visible efforts put in by the doctor and relief from the suffering.*** • ***Polite and humane behaviour, thorough examination and appropriate treatment reliving the condition*** • Flexibility of asking some additional information and queries to the doctor; flexibility of demanding some clinical examination; flexibility and possibility of receiving treatment as per demand in terms of demanding specific medicines or formulations, injections and procedures, flexibility of getting admitted in hospital on demand and getting procedures and elective surgeries done on preferred date etc.	nurses • ***Treatment is not started immediately, promptly and efficiently*** • ***No treatments or unsatisfactory and delayed treatment in less polite manner*** • ***Irrational or un-necessary treatment*** • ***at higher cost***

Chapter-5 Quality Considerations from Clinical Care

Introduction

Discussion with community members about their care-seeking experience showed that a significant part of their reporting of experience was on different dimensions of their (patient and attendants) interface with doctors. The purpose of visiting a healthcare provider or institution was specific, and naturally crucial activities done by healthcare providers towards that specific need constituted the bulk of their memory of care-seeking experience and assessment of that experience. Different dimensions/components of interface with the doctor that emerged while discussing their care-seeking experience ranged from demean ours and approach of doctor to the attendants, patients, and illness; options offered; the treatment given; care provided; relief from the suffering; professional advice given; counselling done, etc. All these dimensions/aspects of interface with the doctor are discussed here under the heading of medical/clinical care and constitute one of the crucial parts of the entire care-seeking experience.

5.1 Experience with medical/clinical care

The clinical care experience differed based on the type of interaction as done in OPD or IPD, as the setting of this interaction, responsibilities of the health care provider, time taken for this interaction, etc is different. The OPD-level interactions with health care providers were numerically very high compared to IPD-level interactions. The higher number of these interactions with different healthcare providers for different illnesses brought out varied dimensions relevant to understand how the community thinks of quality. Although numerically lower, hospitalisation care experiences for various medical or surgical care requirements had the advantage a long time spent with health care providers and institutions. This lengthy, continuous, and in-house experience exposed them to different aspects of the institution and types of healthcare providers and enriched their experience. Therefore, the hospitalisation experience also has significant dimensions to offer to understand the concept of quality in health care.

5.1.1 OPD or ambulatory care

OPD care or ambulatory care, usually, was given to minor and routine illnesses. Sometimes major and life-threatening conditions are also treated at OPD. Chronic diseases are usually treated through OPD care unless there is a requirement for continual medical observation or

monitoring of the patient or a need for some intervention. All healthcare institutions have OPD care components therefore all health-seeking experiences had some component of their experience from the OPD setting. Hospitalisation facilities were not available in all healthcare institutions. The number of healthcare institutions with just OPD services was very high and at village and block town levels they were major healthcare providers used by the community.

When approaching healthcare providers, patients with pain and suffering expect that the doctor would listen to their problem, enquire about the issue, do a clinical examination, if required some investigations, and then explain to the patient his professional opinion about the health problem. They expected the doctor to discuss the prognosis of the condition and then give some options for treatment and treat the patient to relieve suffering. However, most OPD-level interactions for patients were inadequate on many grounds with both public and private sector healthcare doctors. The often-mentioned reason for overcrowded OPDs could be one possible reason, However, even in institutions with no rush, and limited numbers of patients e.g. private clinics or in PHC, there is a lot more to be desired from those OPD-level interactions. Patients are usually treated as passive recipients of service who would answer to questions of the doctor. It was often ignored that patients might also be curious to know about the disease condition. Knowledge about the disease condition might help patient in managing the illness to some extent. The satisfactory dialogue in OPD consultations was expected by most of the respondents. The consultations which make patients well informed about the disease condition and enables to contribute to management of own health was especially stressed in chronic disease conditions. *With the onset of ankle joint pain, the parents of Anmol initially took him to a doctor at PHC in their village. Treatment from PHC was taken for a few days, but the condition did not improve. Then he was taken to Dr. Sugadekar, the medical officer of the rural hospital at Kandhar. For some time, treatment was taken from Dr. Sugadekar with partial and symptomatic relief. The condition would reappear after the prescribed course of medicines is over. Then they decided to take him to show the specialist doctor at Nanded. In Nanded, he was first taken to the private hospital of Dr. Pagare, MS (gen. surgery), this particular doctor was chosen based on their past experience of taking treatment for their family members and relatives from Dr. Pagare when he was working as a medical officer of the rural hospital at Kandhar in the past. Dr. Pagare after examining Anmol referred him to Dr. Tungawade who was an orthopedic specialist. Anmol was on Dr. Tungawade's treatment for some duration, resulting in partial and*

symptomatic relief. With his treatment also, symptoms would reappear after prescribed course f medicine is over. After this, they consulted with one ayurvedic doctor in another town who was known for treating ailments like this and took treatment from him. Few local traditional herbal medical practitioners were also contacted and resorted to the treatment by Anmol's family. One of the faith healers had told them to tie the root of a plant on his arm. They even tried that also. They had visited many places in search of cures from traditional health practitioners. Parallelly, they also searched for and took treatment from many specialist doctors in different private hospitals at Nanded. They had visited Dr. Narsale, an orthopedician, in a private hospital. Here he had been given some medicines which also gave partial symptomatic relief. Other orthopedician visited in Nanded were Dr. Akash Chavan, and Dr. Dubbewar. Some of the doctors had advised him for some radiological and blood investigation. He had undergone prescribed blood tests and x-ray examinations too. ***They had visited every doctor and specialist with all the previous medical records. They tried to ask every doctor they visited about the condition Anmol was suffering from and the diagnosis, but none of the doctors explained to them the nature of the illness. None of the doctors in government or private hospitals explained to them the nature of the disease, prognosis, nature of the investigation and the treatment needed, and the duration of the treatment required. They expressed their urge to know the condition affecting their son for such a long time. They spoke about their inhibition to ask doctor for a diagnosis of the disease for fear of the doctor snubbing them. They feared that doctors might ask them what they would do by knowing the diagnosis and what do you understand about different diseases. They also feared that asking a doctor about the diagnosis might upset him. With all these concerns in mind, they tried to ask most of the specialists they visited about the condition affecting their son. However, none of them gave any diagnosis, nor did they explain the prognosis of the condition. Most of the doctors they visited told them to try the prescribed medicines and assured them that it would give them relief. Most of the medicines also gave relief but it was short-lived relief. The parents were worried about the condition and suffering of their son.*** *This suffering also has affected his education, as his pain is usually in the morning, coinciding with the school timings, and pain affects his studies and school activities.*

Sometimes doctors, private sector specialists included, don't answer patients' queries about the nature of the illness and prognosis. *Arvind visited a skin specialist, Dr. Sujeet Deshmukh, at the*

district town Nanded. Here he was diagnosed to have psoriasis. He was given some medicines to eat regularly and was told to avoid the sun. He asked the doctor what psoriasis is? How does it happen? Why did it happen to me? However, the doctor just told him that psoriasis is also called psoriasis in the Marathi language. The doctor chose not to answer his questions or address his concerns. Instead he told him just to eat the medicines regularly, and he will be alright. He took treatment from Dr. Sujeet Deshmukh for almost two years. However, here also, he did not get any relief or improvement.

Later he started taking treatment from Dr. Darshan, another skin specialist, for the last two years after flaring up of the disease. He asked this doctor also, about the cause, nature, and prognosis of the disease, but he was not given any information or explanation about this. Despite enquiring with two skin specialists and taking treatment from them, none of them explained to him the nature of the disease. Here he was given some medicines to eat and was advised to avoid sunlight. He took treatment regularly for two years without any improvement in his condition. Toward the end of the second year, the doctor told him that the treatment was just for halting disease progression and not for the cure of the ailment. Now he was worried and was wondering about the promise given by the earlier skin specialist who had told him that he would be alright if he takes the treatment. He expected, treating doctors should have given him a choice and helped him make an informed decision after due explanation about the disease, its prognosis, and available treatment alternatives, with their merits and demerits along with success rates or failure rates of these modalities. At least before starting treatment, they should have told him about the disease's success rate or prognosis with the treatment they were offering. He was made to spend money on consultation and medicine. He lost money, time, and energy during this time when the treating doctors were aware of their treatment's limitation and inability in tackling the disease. Not only did he lose the money and faith, but he also lost important time hoping for getting better based on their promise and during this time, his disease flared up and spread all over his body. He said 'he could have used that time to explore and try different alternative treatment modalities'. He wondered if the treatment being offered to him was only for extracting money from the patient as long as possible or until he loses hope and stops visiting the doctor.

Regular interaction with the doctor consists of narrating complaints of symptoms to the doctor. Then doctors ask a few relevant questions and do basic examinations like temperature

assessment with hand, pulse, and BP examination, usually done by private practitioners and, if one is lucky, in a government hospital. Doctors then write a prescription, cursorily explain on that prescription pad how these medicines are to be taken, and hand it over to the patient for purchasing medicines from the medical store. These interactions last for 2-3 minutes per patient in busy government hospital OPD and 5-10 minutes in private practitioner/specialist OPD. Arvind *recollected his treatment experience in the private hospitals and said that he often had to wait for 5-6 hours to get a consultation. During this visit, doctor will ask him about the complaint and then order him to take off the clothes then, the doctor just sees the lesions and write down the prescription and hand it over to him. None of the doctors even touched him. He was then told about dietary restrictions and called for the next visit after one month. Thus his 6 hours wait was for maybe of a six-minute consultation, in which the doctor did not even touch him. Thus there was a complete lack of warmth, caring, and sincere attitude in the consultation process. Now he is admitting that the nature of treatment that he received from private might not have been any different from the government hospital.*

Patients usually are not given any information either about the nature of the illness or about possible treatment options with their advantages and disadvantages. It is usually assumed that the treatment prescribed is the only option available. This type of interaction doesn't help the patient to make informed choices about the treatment received. If the cost of treatment is higher, then the tentative cost of care is informed to the patient so they can mobilise the required money. *In Nanded, Mayabai visited Dr. Bawadekar's Hospital, a multispecialty hospital specialising in surgery, gynecology, pediatrics, and medicine. Dr. Bawadekar was consulted here for her condition.* ***He ordered a USG examination on the patient. They got a USG abdomen study done from the one diagnostic center. After going through the USG report and after examining her, Dr. Bawadekar told them that she had stones in her gallbladder. He said to them that she would need an operation to remove her gallbladder. The total cost of the procedure was around 18-20,000 Rs****. He advised them that they should get the operation done in the coming 15 days. He further told them that if they don't want the surgery from him, they might have to go to Hyderabad or Bombay for further treatment. (There are many surgeons in town who do the surgery for removing gall bladder; there is a full-fledged surgery department in the medical college hospital that regularly does this surgery.) He prescribed her some medicines for a week and told them to come prepared for the operation.* Though it was not articulated as such by her

and her family members, it appeared that the advice given is not only inadequate, it is wrong and motivated. Such wrong advice was observed in other interviews with patients, especially after examining the available medical records.

Wrong and motivated diagnosis of a disease condition and its treatment has a lot of implications for the patient and their family. *Tanaji is married for nine years. The couple doesn't have any kids. They have shown some private hospitals of a gynaecologist in Nanded to take opinions and treatment for their infertility. The couple was put through various diagnostic tests and treatments. After spending a lot of money and with his mother's illness, they have now stopped treatment for their infertility. However,* ***Tanaji told that the doctor treating their infertility had said that one of his wife's tubes was blocked and she needed surgery to conceive.*** *Previous medical records of his wife were not available for comment.* ***He showed (to researcher) the investigation reports available including the semen analysis report. The doctor had told him that his report was normal. Doctors had advised them of further investigation and treatment for his wife's blocked tube. However, the semen analysis report of Tanaji was not normal (as shown to me); it showed azoospermia. When told about inadequacies in his report, he told that doctor had told him that his report was normal.***

Despite patients paying money for the services, the doctors' professional services were often inadequate even in terms of giving professional opinions or at least differential diagnoses of the condition they are treating. Sometimes there was a wrong diagnosis and advice given, raising suspicion about it being financially motivated. In government hospital OPDs, the inadequacy of time given to the patient raises doubt over the entire interaction of care-seeking. Patients have many questions, like whether the doctor has even understood the health problem. If requested for more time and attention to be given to the patients, it is often not given or it is not possible especially if OPD is overcrowded. *Krish's uncle told that even if they have to spend a little extra,* ***it is very important that the doctor talks to them satisfactorily, and that the patient gets better from the ailment.*** He said *"we will buy medicines from outside if doctors want but a doctor should talk satisfactorily and cure us from the ailment. In a government hospital, expenditure is less but nobody talks satisfactorily and humanely." Then Sumanga added that the PHC has a stock of medicines but the hospital staff never satisfactorily spoke to her and gave her*

*medicines**. He then said 'in government hospitals, doctors don't examine properly; then they tell them to bring medicines from outside, they neither explain to them anything about the medicines, the purpose of the medicine, estimated cost, where to bring it from nor do they administer the bought medicine to the patient immediately.** If relatives or the attendant, ask the hospital staff about some concerns and doubts then they are not answered or explained properly. In fact, the chances of getting rude answers are more, and after that, they feel insulted and then avoid talking to these staff members, usually sisters. **If requested to see or attend to the patient, then the doctors or other hospital staff do not come in time**. Whereas **in private clinics, the doctor examines them properly, writes the prescriptions, and explains where to bring the medicines from, the probable costs, and sometimes the purpose of the medicines used. They even administer these medicines without any delay.** If a patient or the attendants ask them about their concerns and doubts, even sometimes repeatedly, they are responded to satisfactorily. **The doctors or hospital attend to the patient whenever requested without delay'.***

When assessed with a thoroughly professional approach to understand the nature of the illness to relieve suffering, patients understand and appreciate that care-seeking experience for its scientificity and genuineness. *Bhagirath tried treatment given by PHC, CHC Loha, and the government medical college of Ambejogai in the nearby district of Beed, for his neck pain. None of these institutions, despite repeated visits and completion of prescribed treatment, could provide relief from pain. At the suggestion of friends, he went to Ayurvedic medical college and hospital at Nanded. He was seen first in the OPD. Here a detailed history was taken along with a physical examination. For the first time, he felt that his illness was taken seriously. The reason for this feeling comes from the experience that he was asked whether he had lifted any heavy weights, had any incident of fall or accident, or any relevant history of injury to the neck. There was no such positive history but he felt that doctors were serious about understanding and attending to his ailment along with doing something to intervene in the condition. A thorough physical examination was done where power in his all muscles of the upper and lower limb was checked. He recollected this experience when doctors had told him to hold his hand tightly and pull and push the doctor's hand. His weight was taken and traction was given keeping his weight in mind. A X-ray examination was done, and new and old X-ray was reviewed. He was advised to get admitted. He agreed and was admitted to the ward meant for musculoskeletal ailments.*

Reflecting on their entire care-seeking experience, they also tend to revisit their opinions about the doctors they have received care from. *Pitamber waghmare, recollecting this experience from a private hospital doctor told, a doctor from Hyderabad had actually identified the illness correctly. Pitamber had visited the doctor for pain in the neck. The doctor, during his clinical examination, had asked him if there was a sensation of a hand like holding sand in a fist. He actually had those symptoms and the doctor had guessed it right. The doctor advised a CT scan examination. Pitamber preferred going to Nanded as there was social support. In Nanded, after going through a few doctors and a CT scan examination, the nature of the illness corroborated with what was predicted by the doctor from Hyderabad.*

Additional concerns were raised by most of the community members about treatment provided by a government hospital, especially from PHC and RH. They had doubts about the treatment being disease-specific. ***He then complained that the same medicines and tablets are given for different illnesses.*** The community members often mentioned that government health centres have few medicines available, and the doctors prescribe the same set of medicines for all kinds of illnesses. This practice raised their suspicion on doctors' ability and institutions' capacity to treat diverse health needs of the community. They thought that the doctor was merely doing the formality of prescribing some medicines, and getting rid of the patient from OPD with no concern for relieving suffering.

Community members reported that PHC and RH were providing only a few types of medicines for diverse illnesses. They were also aware of the enormous diversity of medicines available and the specificity of these medicines for their use. When they are concerned about a few types of medicine being available in PHC, they are not necessarily asking for more medicines to be given to each patient. They recognised the need of using medicines appropriately. *While showing the drugs Radhabai had taken from these private practitioners they told that doctors prescribe many medicines. Dr. Gudewar's prescription was available and it contained almost 7 medicines to be taken daily orally. Her son believed and told that doctors were also not sure about the condition so they gave a combination of different medicines in the hope that either of them would work. However, the patients have to bear the costs of these medicines. Doctors also have cut practice with the medical stores and earn some percentage from the total sale of the medicines from these drug stores. Her son said that doctors' tendency to prescribe many medicines raises doubts in*

their minds about the doctor and the usefulness of the medicines prescribed. He added that there is no choice but to go to these private practitioners.

Community members have their own ways of understanding/perceiving different diseases- the nature of the illness, its cause, and prognosis, especially of common illnesses they encounter. These perceptions are shaped based on their past experience of illness, the experience of illness of others in the community, and what they have heard and seen from care-seeking experiences with diverse healthcare providers. These perceptions are not static and constantly evolving based on their experience. Their worldview of the nature of illness and the type of care needed shapes the care that they choose. It becomes important for them to understand how healthcare providers are thinking about the illness- worldview of healthcare providers. When both the world views of patient's and provider's match, the treatment is accepted easily, if these world views are divergent then it becomes important, how convincing is the healthcare provider in articulating his understanding of the nature of illness and his line of management. Patients are also observant and keen to know how the doctor is thinking of illness and deciding the line of management of illness. If they find flaws, inconsistencies, irrationality, or ulterior motive there, it acts as grounds to discontinue the treatment. Asaya and Madhukar's care-seeking experience for treatment of post-snake bite wounds from the famous snake bite specialist doctor of that area, Dr. Shende, was disappointing. Their response was keeping in mind what they had heard about him (as a noted and famous doctor for snake bites); their expectations from such a famous doctor; in contrast to what advice, treatment and care they received, and the whole experience of taking treatment from him. ***She in retrospect said 'she was very doubtful about the doctor, he might have been a good doctor in the past but based on her experience she doubted the doctor and his fame. She was unhappy with the very cursory and superficial examination that the doctor did of her wound. She doubted the doctor's opinion about the type of snake that had bitten her; she firmly believed that she was bitten by Nag (cobra) while the doctor told her that she was bit by Parad (viper). This further undermined their faith*** *in the doctor.* ***Doctor then further suggested them a list of procedures and operations to be performed on her wound, all of them sounded like very expensive operations. He had told her that she might even need amputation of her leg. Asaya did not think that condition of her leg was so serious, needing amputation.*** *She thought that the wound was large and will take more time to heal but did not believe that it might need so many expensive operations or amputation. (They were aware of and*

known of a person who had been amputated after a snake bite.) ***Doctor's advice of doing an operation at Nanded and following up dressing with Dr. Shende at the cost of 25,000Rs did not sound a piece of convincing advice to them. Doctor's advice of calling him on his mobile after reaching referred private hospital further raised doubt about his intentions (with the background knowledge of trend of cut practice) in Madhukar's mind. So overall experience of lack of sincerity in the examination, the doubtful judgment of the type of snake and the financially motivated advice of an expensive set of unnecessary operations contradicted and crashed their belief and expectation of this famous doctor'.***

OPD medical consultations are important events for patients, they had taken an effort to travel to the doctor with illness in order to get consultation and treatment. Most often, the patient is paying for this consultation and the expert opinion of the doctor, apart from separate payments for purchasing medicines from the medical store. It is expected that doctor documents the nature of the illness, his observations, and findings, along with advice and treatment suggested on paper, and is given to the patient as a matter of medical record. This medical record is required during follow-up visits for ascertaining changes in the health condition. The nature of documentation (of illness, examination findings, test results, differential diagnosis made, and treatment given) done by the doctor and given to the patient also indicates the quality of that interface with the doctor. Patients or common people are usually not in a position to make an assessment of medical records given to them. However, during the discussion with community members about their care-seeking journey, most of them brought out their medical records and shared with the researcher, therefore it was important to include and discuss it here. *On asking her (Ujala) further questions related to burning micturition, she told that she had a burning sensation in her genital region, white discharge, dysmenorrheal, and nausea. So this was a different complaint altogether as compared to what was being articulated so far.* ***Multiple papers available with her about her consultation did not mention any complaints, most of the consultation papers only wrote a list of medicines. Few consultation papers mentioned complaints of burning micturition in half a line. None of the consultation papers, she had with her to show it me, had written notes about the general examination, and the systemic internal examination done on her reproductive tract. So it is very difficult to decipher whether her complaints were articulated in the appropriate manner by her to the doctors she was visiting in the short duration of time that doctors gave to her and whether the doctor understood her***

problem clearly. *It is not clear whether she was treated for burning micturition, UTI, or for the burning sensation in the genital region, or dysmenorrhea. If the notes on the examination were available in the medical records, then there was the possibility to make sense of what kinds of the symptoms were reported and sign were present along with examination findings and about the probable diagnosis or differential diagnosis.* ***None of the consultation papers mentioned anything about differential or probable or definitive diagnoses doctors had considered while prescribing the medicines. Medical records handed over to the patient had very little information to decipher anything about the past medical condition of the patient. This was observed in most of the medical records available and shared by the respondents.***

Medical records available in the form of different diagnostic test results were available with many patients. However, discussions with patients revealed that, at times the communication by doctors with the patient regarding the test results did not match with available test results. This was observed in multiple cases. Earlier in the case of Tanaji, it was observed that doctor had told him that his report was normal where as his semen analysis report had documented azoospermia. ***In the case of Ujala, two USG reports were available with her, both of them were done at Pune six and three months before the date of this interview. Both reports had shown a normal uterus with no evidence of fibroid or any other anomaly of the uterus. If one goes by only these two USG reports then it raises doubts over the advice of hysterectomies given by the private hospitals. Before her visit to Pune, the private hospital of Dr. Trishila in Nanded had told her that she had fibroids in her uterus and needed a hysterectomy. If she had fibroids in her uterus, then it is less likely that the fibroid had resolved and disappeared. The USG report was not given to the patient by Dr. Trishila so it was not available for comments. She was advised hysterectomy even in a hospital in Pune, though the USG report did not mention any fibroid that they reviewed. It is unclear what could have been the indication for which they were advising her hysterectomy. The patient was also not told about the indication of the hysterectomy, but the patient assumed that she was having fibroids in the uterus.*** In this situation of patients' ignorance and inability to read the available medical records, one is forced to think about the possible indications. One can think about cervical cancer or dysplasia, but she was advised about the operation on the same day she visited the hospital in the OPD after reviewing the USG report, so it is less likely that a Pap smear test was done. Even if done then reports might have been given to the patient. It is less likely that doctors won't explain if a pap

smear or any other test is done to diagnose cervical cancer or cervical dysplasia, a serious and potentially life-threatening condition to the patient. Cervical cancer or dysplasia is less likely the cause for a 30 and 34 years old. If one considers cervical cancer or dysplasia as less likely to be her condition, then the symptoms can be due to bacterial or fungal vaginosis. The persistence of symptoms despite antibiotic treatment can be explained by the phenomenon of ping pong re-infection from her husband, as he has never been advised of any treatment, and none of the doctors they visited had advised them to get treatment simultaneously. If she is suffering from this condition a hysterectomy is not an option to be considered. Her symptoms of excessive bleeding during menses either need hormonal treatment or a dilatation and curettage procedure before one can think of a hysterectomy at this early age. If hysterectomies are done at this early age, then there are chances of vault prolapse in later years of life. **The whole patient's narrative of her complaints and the available medical records of the different diagnostic tests, specifically USG reports raise doubts about the motives of private hospitals who were advising her hysterectomy. Hysterectomy at this early age for complaints of burning micturition, burning sensation in the genital area, white discharge, and excessive bleeding during menses raises doubts rationality of the advice.**

5.1.2 IPD: Valuing professional expertise, attention, and a caring attitude

Hospitalisation care, given its very nature exposes patients and attendants to various components of the hospital and gives them experience with various aspects of the care process. Some of the components of the care process like para-clinical (a term used for the lack of a better alternative word to denote care given by other health care professionals like Physiotherapists, occupational therapists, and speech therapists) care and nursing care are discussed in the next chapter. Sanitation, food, and other support services are also discussed in the next separate chapter. This chapter is focusing only on the interface with the services of a doctor. Of the total interface with the doctor, only clinical skills and medical rationality-related components of care seeking journey is being discussed here in this section. Other components of interface with the doctor like his efforts in the care process, the effectiveness of his interventions, comprehensiveness of interventions used, inter-personal communication, etc. are discussed in this chapter's subsequent sections.

Hospitalisation is done usually for serious illnesses and for health conditions requiring constant supervision and monitoring by healthcare workers. Therefore, when admitted, patients and attendants expect that patient is given frequent attention, care, and treatment so that patient will be safe and discharged soon from the hospital. *After reaching the Padam hospital Sulekha was admitted there.* ***The doctor took her history, examined her, and told her that she had lost all her amniotic fluid and that her condition was serious. (*****Patients and relatives are constantly kept under the impression of the worst-case situation or made to believe that condition of the patient is serious so that possible complications or undesirable outcomes can be attributed to the seriousness of the ailment and if the outcome is good then the doctor earns good respect and money. It's being raised here as she was given a trial labor of about almost 20-22 hours in this hospital.***)** *Her relatives, parents, and father-in-law, requested the doctor to try a normal delivery.* ***The doctor too promised them of doing normal delivery after examining the patient. She was given a trial of labour after her admission at around 4 am in the morning. Throughout the day she was in the hospital and was constantly examined and monitored. (She was operated upon with a caesarean section late in the night to deliver the baby; this experience around surgery is discussed in another chapter.)*** *While discussing other facilities and brighter aspects of the services provided at the Padam hospital, father in law of Sulekha told that* ***the hospital gave prompt and frequent attention to the patient and they were very appreciative of this feature of the service provisioning****. (Being a small hospital of 6-8 beds with 2 doctors, it would have been possible to attend to the patient quickly.)* **The prompt and continuous attention of which they were happy and appreciative was rather given to them to treat one of the complications, though minor, she had developed. Though they are unaware of the seriousness of such an incident, they were not even informed about it. She had developed a fever and suture wound infection. She received all the attention to tackling this complication. For serious ill health, requiring hospitalisation, frequent attention, and visible efforts by a trained doctor is what the patient and attendant can ask for and can do for the patient. This demand is made with the assumption that through that attention and effort doctor is using his professional knowledge and skills in the best interest of the health of the patient. That is usually the case, no doctor or healthcare provider would want to harm the patient or push a patient into ill health.**

Usually while admitting the patient, doctors tend to create an impression that illness is serious and sometimes health condition is serious too. This panics the attendants of the patient. A confident behaviour and dialogue explaining the nature of the problem and assurance of treatment make a lot of difference in the psychological status of the patient and attendant. Reassurance is usually what is expected during hospitalisation from the doctor by the patient and attendants. However, doctors project a worst-case situation so that managing situation around the treatment of illness becomes easy for them. There is a thin line of difference between assurance and guarantee. Eroding doctor-patient relationships and mutual distrust towards each other are causing an increasing demand for a guarantee of cure by patients and increasing reluctance to give assurance and confidence of better outcomes from doctors. *Nayan gave a recent example, where one of his grand-daughters had a fever and then developed seizures when they were in their field. She was immediately brought to the PHC. She was referred to Kandhar. Nayan took her to the private hospital of Dr. Adhav. While comparing both these experiences at PHC and Dr. Adhav's hospital family members told that they liked and were happy with the treatment given at Dr. Adhav's hospital. They expressed their dissatisfaction about the services provided by the PHC doctor.* ***The positive attitude towards Dr. Adhav's treatment comes from the fact that doctor had examined the baby thoroughly, doctor himself had wiped the baby with a wet cloth repeatedly. He took a blood sample from the baby and gave it for sending to the lab. Then the baby was put in an IV cannula and given some injections. Further treatment was given based on the blood report. He was equipped to do blood tests and provide whatever treatment was needed. He did blood tests and gave her some injectable medicines and admitted the baby. He also gave further treatment to take. Thus Dr. Adhav immediately examined the patient and started intervening quickly as seen through his action as he was doing. These actions in the form of various activities aimed at treating the baby gave them some confidence. They felt hopeful and confident as something was being done by the doctor, who knows about the illness and the treatment. He gave them a feeling of confidence; he displayed confidence in his behaviour. He gave them assurance of treating the baby. Reassurance from the doctor about curing the baby was very important to the family. Thus the confident behaviour backed up by the infrastructural facilities to investigate and treat the patient along with a caring attitude and assurance about curing the baby was very important in this family's positive attitude towards Dr. Adhav.***

Lack of required medical attention and sincere effort by the doctor is seen as depriving the patient from restoring health. Such a negligent behaviour of the doctor is a serious matter of concern. If the illness is perceived as serious- any insincerity, delay, or irregularity in the assessment of the patient and required intervention becomes a grave concern. This insincerity is usually a reason for patients, attendants, and community members to become agitated and angry with the care provider and institution. Insincerity, delays, and irregularity in the monitoring of the patient and lack of required medical attention were often important reasons for not using government hospital services or as reasons of poor experience from a government hospital. However, this kind of experience was not unusual in private hospitals also, and this acted as the reason for the change to another private hospital /provider. *After the caesarean section on Sulekha at Dr. Adhav's hospital, Nayan was reluctant to admit his new-born grandchild to Dr. Khure's hospital (maternity and child hospital with gynaecologist and paediatrician couple) given his past history of poor experience at this hospital. However, with persuasion by Dr. Adhav, explaining the seriousness of the new-born's health condition and with the lack of alternatives in town, the baby was admitted to Dr. Khure's hospital immediately after birth, late in the night. When they went to see the baby in morning, the baby's condition was very poor. The family was upset with the baby's condition and demanded immediate discharge. The paediatrician Dr. Khure refused the discharge and told them to come in the afternoon and discuss it with her husband in charge Dr. Khure. In the afternoon Dr. Khure came back to the hospital, and he assessed the new-born baby. He told them that the condition of the baby was poor. He further told them that there has been negligence of the baby from their side.* ***After doing work at their own hospital and after the operation (of caesarean section to deliver this baby) at Dr. Adhav's hospital they were tired and they went off to sleep so they could not monitor the baby well. He told them that he had seen the baby at 4 am in the morning; that time baby was well, but somehow, the condition of baby worsened. He told them to take the baby to some other hospital as per their wish.*** *Then Nayan told him 'you have refused us discharge when we asked for it, now keep the baby admitted in your hospital but if something goes wrong with the baby then be ready for the consequences'.* ***He had asked for the baby in the morning 9 am and Dr. Mrs. Khure had told them to take the baby away after 2 pm.*** *Before leaving the hospital Nayan told Dr. Khure that he was ready to pay whatever it costs, but won't take the baby until the baby was normal. He along with his relatives left the hospital and went to*

Dr. Adhav's hospital to attend to the baby's mother admitted there. Then one attendant from Dr. Khure's hospital came along with the baby behind them and he handed over the baby to them and the bill of 3000rs. They paid the bill to him and took the baby. The baby was later admitted and treated at the pediatric hospital in an adjacent town.

Lack of attention, sincerity or partial attention and the tubular vision of the disease condition and neglect/disregard for the overall health of the patient was also a matter of concern. *Asaya also shared an experience of one more case from the village of a* ***young boy who had post epileptic fall and head injury and developed hemiplegia. He was admitted to Dr. Raj Adhav's (Neurosurgeon) Hospital, they also had a very bad experience in that hospital. After a few weeks of treatment when the parents realised that there was no improvement in his condition and he had paralysis they asked the doctor about the paralysis of the body, the doctor replied that he was a specialist in the brain and he was treating his head injury, so he was not answerable to paralysis in limbs. They had spent a huge amount of money (2 lakhs) and sold off their land to pay the bill. During the course of treatment and after discharge, there was no advice from the doctor for physiotherapy and speech therapy; not even a suggestion for doing massage and movement of limbs. Lack of physiotherapy and massages had resulted in contractures in his limbs. He lives with residual paralysis and contractures.***

Regular expert attention and care were considered important; some even made demand for that attention during hospitalisation. The demands are usually made to the nurses, and that experience has been discussed in the next chapter. There is diffidence while demanding regular attention but some attendants do gather courage and demand that attention from the doctor also. *Purushottam Waghmare said that if such demand for regular and timely attention is made, doctors from government hospitals either ignore such demands or retort saying that if you are in hurry or need personalised attention, then go to a private hospital.* This implied that doctors also are aware of irregularity and delays in the treatment being given.

The value of regular attendance and attention of the doctor during the course of hospitalisation was reported for timely changes in the line of treatment if needed depending on changing patient health condition. The treatment was expected to be dynamic, and appropriate to changing nature of the condition of the disease. *Talking about his experience in Tayar hospital, the not-for-profit*

trust hospital, Shambhu said that many doctors were visiting there from outside as consultants. The treatment orders given by these consultants were usually followed. However, the numbers of visits of these consultants were few and not regular. ***So changes, if needed during the course of treatment, would get affected (for lack of regular visits by specialist consultants).*** *However, the hospital was good for the poor as it provided treatment at minimal costs and provided care without any tendency or urge to get rid of the patient before the relief from the ailment.*

Most of the community members, while reflecting on their hospitalisation experience, preferred regular expert attention, examination, and monitoring. This demand differed depending on the nature of the illness or health condition also. They also expected gentleness and dignity during these clinical examinations and medical interventions. *While comparing home delivery and hospital delivery she (Anita) preferred home delivery. During hospital delivery, she was examined regularly at intervals by a nurse till she got delivered.* ***She did not like these frequent internal examinations and the way it was being conducted by the nurses. She detested those repeated internal examinations done by sisters. These internal examinations added to her labour pain. She had objected to those repeated examinations. The nurse doing the examination also got angry with her and told her to leave the hospital if she doesn't want the examination.*** *During home delivery, there were no such internal examinations.* Partly the reported difference can be due to the fact her first delivery was done at the hospital, and the first delivery is usually difficult, painful, and longer and needs internal examinations at regular intervals. However, the number and frequency of such examination and their impact on patients' overall experience in the hospital need to be investigated further.

In addition to medical intervention in the form of medicines or surgical procedures, an explanation of the disease condition and advice given by the doctor for treatment and care also mattered to them. Those experiences of care from an institution that consisted of engaging patients actively in understanding and relieving suffering were fondly remembered as good practices. The doctor's practice of explaining about nature of the illness to the patient, explaining the line of management and nature of the treatment, and how it might benefit in relieving suffering was an enriching and empowering experience for the patient. This practice made them feel treated with some respect and dignity. This practice enabled, empowered, and motivated them to take an active part in healing themselves. Few such experiences were fondly recollected

as the best experiences by the patient and were from government hospital settings with a lot of infrastructural and human resource scarcity. *Bhagirath with his chronic neck pain, on advice from friends about the possibility of treatment and good care free of cost with the provision of the facility of two times meals, gave the confidence to try treatment from government ayurveda medical college. Here history of illness was taken properly and a thorough clinical examination was done. An X-ray examination was done and new and old X-rays were reviewed. Bhagirath was advised to get admitted. He agreed and was admitted to the ward meant for musculoskeletal ailments. On admission, regular treatment involved some oral medicine of which some had to be purchased from the market, and some provided by the hospital. Bhagirath was given regular massages on his neck. Some herbal oils were applied while giving massages. A hot paste made from boiling different herbs was applied to his neck regularly. A small heap of black gram flour was made on his neck and some hot oil was added to it, this was a kind of hot fomentation with hot oil. After keeping it for a few minutes, someone from the hospital used to give a thorough massage on the neck. He was also given steam on his neck. He was given cervical traction with a belt tied on the neck and head with some weight attached at other end. This process was done by hospital staff, doctors, nurses, or other supporting staff in the beginning. Later he was taught how to apply traction and change weights and remove weights when there was a pain in the neck. He learned the process of applying and changing the weights of traction. During the treatment process, he was told that there was a problem with the 'manka' (neck vertebra). For the first time, someone had tried to explain to him the condition he was suffering from. After the first few days of hospitalisation, he did not need any attendants to be present with him. It helped in cutting down the cost of his care completely, and his family members were spared from getting affected due to his treatment. Whenever needed, he used to go across the hospital to the market to buy medicine and material prescribed from outside the hospital. He had become friends with fellow patients admitted to the ward. So he did not feel lonely. He said that the hospital staff was supportive and helpful. He appreciated the personalised treatment, attention, and care he received in the ayurvedic hospital. The hospital staff was directly and personally involved in providing care by putting in their physical and mental energy.*

5.1.3 Wholesome treatment

Wholesome/ comprehensive treatment comprising of right interventions and advice which relieves suffering was considered good treatment. The wholesome treatment should be according to the nature of the illness and should make use of diverse expertise if needed in the treatment process to restore health. Advice on the role of other professional interventions, without feeling competition from them, to maximise health benefits to the patient was considered a better way of managing illness. *In this Ayurveda hospital, Shambhu felt that he was cared for as* ***he was getting personalised care****. Here he was admitted for almost 2 months. For the first time, he got explained the nature of the illness and prognosis here.*

He was told here for the first time that he had an injury to his spinal cord, what is the spinal cord, its structure, and function, the chances of improvements and precautions he needed to take, and the exercises to be done. Here doctors cared to talk to him and spend some time explaining the nature of his illness and some of the doubts he had in his mind. ***Doctors and other hospital staff were talking to him, spending some time with him, helping him in doing his exercises****. There were some professional masseurs available, though they were not hospital staff and had to be paid for from one's own pocket. However, they were allowed to do massage of a patient with different kinds of musculoskeletal disorders and paralysis.* ***These massage sessions have a very great deal of importance in Shmbhu's whole experience of illness and treatment, where he felt that he was cared for, and somebody was investing time, energy, and skill to get him better. He was told about the importance of massages and exercises.*** *He already had developed contractures in his palms, elbows, and foot. There was wasting in the hand and lower limbs. With the massages and herbal hot fomentation, there was an improvement in his condition, his contractures showed some relief and with more power in his both limbs, he could stand with the support. When he realised that* ***his contracture got relieved with the massage and exercise*** *and he was told that these contractures could have been avoided if he had taken advice from the physiotherapist and done exercises and massage from the beginning.* ***In this hospital, for the first time, he was told about the physiotherapist and their role.***

5.1.4 Malpractice and unnecessary interventions

The practice of unnecessary investigations, prescription of medicines, and surgical procedures to earn more money by health care professionals, especially in the private sector, was discussed by almost all respondents. Malpractice by doctors has become common knowledge in the community. It was often conveyed directly using harsh language and sometimes indicated as the given context. This malpractice is often done by doctors to earn more money, and robs the patients of their money. This trend of malpractice with financial motives has implications on the health of the people where patients undergo unnecessary medical and surgical intervention, and others don't get necessary treatment or rational treatment, improving health outcomes. The trend of malpractice was discussed as a major problem in the medical profession. *While discussing the* ***rationality of treatment given in government and private hospitals,*** *they said that there were numerous examples where private hospitals have done or advised unnecessary caesarean section deliveries on different pregnant women. Both Bishan and Tanaji thought that* ***private hospitals do unnecessary procedures for investigation, or operation or prescribe unnecessary medicine to earn more money****. They told that private hospitals will do only those operations and procedures which will fetch them more money without putting in more effort and care. They won't do procedures that will have less money or the possibility of complications. Private hospitals are more likely to do procedures that give immediate results (without any consideration for long-term health and betterment of the patient.)* ***The private hospital is quick to act in doing any procedure and operation without trying out a medical and conservative line of treatment as that big procedure or operation gives them more money****. The drawback of the government hospital as they told was that it was more time-consuming. However,* ***the government hospitals, they believed, provide thorough check-ups and complete and comprehensive care****. The* ***chances of getting rational care were also very high in government hospitals as compared to private hospitals****. Recollecting his experience, he told that Dr. Bawadekar was only interested in doing the operation for gallstones, whereas the government hospital provided them treatment and cures for her mouth ulcers and burning pain in the epigastric region of the abdomen. They also discovered and treated her heart condition before operating on her to remove the gallbladder.* ***The treatment that they received was without any monetary incentives for the providers. So they considered the treatment was as 'needed and rational treatment****'.*

While recognising the complexity of health care, the community expressed doubt over the rationality of treatment provided, in some cases, had experienced irrational care. However, with increasing experiences of irrational treatment and the rising cost of care, there is serious mistrust among medical professionals.

It was realised that, there is a contradiction in their opinions and practices like, they were doubtful about the appropriateness of care provided and yet had preferred using services of private hospitals. On enquiring about this contradiction, ***Nayan and his family replied that most of the time they cannot judge whether the treatment is right or wrong. They said they go to the hospital with their suffering and even pay money to get better. They told that nobody would want inappropriate treatment. How can/why should a MBBS doctor (trained doctor) give a wrong treatment, how should they know whether the treatment was right or wrong? They would follow whatever was suggested by the doctor. They also said there was a rise in the trend of unethical practice by doctors in terms of unnecessary operations for extracting money. He went on to say that doctors have become like dalals' in the cattle market.***

Harsh comments like this on medical professionals have their own reasons, widely recognised cut practice among medical professionals is one of the reasons. *Keshram further added that* ***the probability of doing the unnecessary diagnostic test was very high at the private hospital***. ***Despite doing many tests the diagnosis can go wrong at a private hospital. Apart from operation costs, private hospital doctors prescribe heavy and unnecessary medicines. He said that most doctors have some linkages with the medical stores where they get some commission and kickbacks. So, to earn more money, doctors prescribe lots of medicines, which are usually unnecessary. So chances of getting irrational treatment were high at the private hospitals. He told that chances of getting a correct diagnosis of the condition and rational treatment were high at the government hospitals. This was another important reason for choosing and grading the government hospital as better as compared to private hospitals.*** *He told that private hospitals have reduced to institutions extracting as much money as possible from the patient in every possible way. Running entirely on profit motives they can go to any extent to earn money.*

While there was recognition of the value of rational treatment and of the widespread practice of unnecessary diagnostic tests, medicine prescriptions, admissions, and surgical

procedures, it was also expected that the treatment is provided with some manuski (human nature) and with responsibility and accountability. The most important thing for them was to get treatment first and then the question of judging the nature of the treatment. On asking about **the rumour among people about the increasing unethical practice of unnecessary prescription of medicines, tests, and overcharging** ***he (Kisan's uncle) said that there is no way and the possibility of checking or knowing that as a lay person and there is no scope for negotiation or refusing or non-compliance as health and life is at stake.*** *He compared the medical profession with the lawyer where professionals have nothing to lose, whereas the client or patient has everything at stake. To annoy or displease the doctor or lawyer means taking a lot of risks.* ***He said that if we don't comply with the doctor or if try to negotiate for the money; then he might keep the patient for some extra days in the hospital (given the power position doctor has multiple ways of twisting the situation to his benefit and it's difficult to understand and negotiate with it).*** **Talking** about **proficiency or ability or capacity to do correct diagnosis and give rational and proper treatment** ***he said that there might be a small difference in these professional capacities of doctors from the public sector and private sector***. However, he then went on to say that, ***doctors at the government institutions don't have patience and manuski i.e. human nature and skills to interact with patients and the attendants***. *Later he told that with the fixed salary per month, performance is not really a concern of* ***the government health professionals, so they don't really take an effort to treat patients. Government doctors don't want to take responsibility, so all the time they want to send the patient away at a higher level out of their jurisdiction or at least out of their institution. If they admit the patient or keep them under observation, then the doctor will have to wait at the PHC or in the institution till the patient gets better. Admission of patient restricts doctors mobility, he cannot go away. The PHC level doctor is coming here for fixed hours so he will see to it that all responsibilities are taken care of and completed before he leaves the PHC.*** *(Whether it is a defensive practice or lack of skills, lack of material conditions to treat patients completely, or mere lack of tendency to put in efforts to treat patients?) When asked about the popular belief that* ***private doctors give good care he told that it is not about good or bad first, but it is about whether treatment and care are given or not. Private doctors give care quickly and charge money for it, whereas the government. doctors don't start the care and treatment soon and when started they don't even give it in a satisfying manner with a caring attitude. The patient***

is neglected quite often by government institutions. *They give treatment and care rudely and disdainfully. He then said that* ***if we get relieved from the symptoms then we call that treatment as good treatment.***

5.2 Relief from suffering as an important consideration in care seeking

The patient's primary motive for seeking care is relief from suffering and a cure for illness. Healthcare providers' main objective of the treatment and care given is to relieve suffering and cure illness. For community members, the most important criterion for assessing or evaluating the health care provider and the treatment is whether there is relief from the symptoms. If they recover from the disease and are free from suffering, then they consider the treatment good. Further, they did not mind recommending it to others and revisiting the same provider or institution in the future. *Doctors in the government medical college and district hospital, after a thorough examination, advised Mayabai that she should take some prescribed medicines from the hospital and come back after one month (she will be then fit for anaesthesia required for gall bladder removal surgery). If her condition is better next time, she could undergo the operation. Bishan then requested the doctors to do something about her burning pain in the abdomen, loose motions, and mouth ulcers because those were her pressing concerns and taking her home without treating these conditions amounted to keeping her in pain and suffering. He told them that she could not eat properly; she was weak and having giddiness due to the weakness.* ***The doctors then subjected her to another set of procedures. As can be perceived from the interview, it was most likely an endoscopy. She was given treatment in the hospital for a few more days and was discharged after almost 12 days of hospitalization. She could eat, her burning pain had significantly reduced, her giddiness had subsided, and she felt much better****. She visited the hospital again after completing the prescribed treatment for one month at home. This time she was admitted, surgery was done, and her gall bladder was removed after a thorough evaluation with different tests to check her fitness for surgery. She now had no pain and related complaints. The government hospital was chosen based on economic considerations. They shared that their* ***overall experience with the government hospital was better and satisfactory. On asking the reasons for the same, he said that her (Mayabai) illness was treated and cured. She was free from those symptoms and suffering.***

In the era of specializations in medical practice, the experience of relief from illness in the community has also specificities around it. Experience of cure and relief of symptoms from a provider of a healthcare institution is remembered by the community in the context of that particular disease and suffering. The community has its own memory and understanding of the health conditions and relevant healthcare institutions that have been found effective and useful for health conditions. The reputation of institutions and providers is based on terms of what health conditions they are known to have addressed successfully, cured (diseases), and relieved suffering. Depending on that experience, a specific illness or similar illness for which a cure was offered,the health care providers are chosen and evaluated. The common discussions referred to different doctors and healthcare institutions in relation to a specific doctor or institution being good for treating specific types of illnesses. *Ujala was very disappointed with the care she received for over a decade from doctors at PHC, most of the private practitioners at Kandhar, one specialist doctor in Nanded, and a private medical college hospital in Pune as she did not get any relief from symptoms. She had spent a lot of money and time for elusive cure/ relief from burning micturition, dysmenorrheal, and pain in the abdomen. She had not consulted a specialist doctor from a government hospital at Kandhar or Nanded, thinking that if private doctors could not give relief, then it was less likely that she would be cured at the government hospital. S*he, along with her husband and other family members, told that ordinary persons like her donot get proper treatment. (so they will not be seen by doctors and other paramedical workers on time, if and when she would get a chance, the hospital staff and doctors would not talk properly; they would not undertake a thorough history, examination and relevant investigations would not be asked for by doctors; if asked, for they might not be available and if available it would not be done on time and in a humane manner; substandard medicines or insufficient medicines or not so effective medicines will be given). *On further probing about if they have ever visited the government hospital anytime, she told that she was admitted there for five days when she had a major head injury and was unconscious and taken there in an emergency. On asking about her experience of five days at a government* ***district hospital, it was revealed that her overall experience was of better care. On asking why they say so because a few minutes back, everybody, including herself, was sceptical about the care given by the government hospitals. Everybody echoed that she (Ujala) got better from such a serious and life-threatening condition; what else do we need? So, getting a cure and relief from suffering was of***

paramount importance in saying that the government hospital was good and provided good care. However, this personal experience and memory of good treatment for such a major life-threatening condition did not inspire her to go to a government hospital and she is learning to live with it as she believed government hospitals could not treat this condition.

While the desire of getting a cure or relief from suffering was unequivocal, the desire for relief, the possibility of relief, and the experience of relief were usually discussed with the price that one has to pay for it. The cost included monetary cost incurred, indebtedness it caused and the experience of humiliation or indignity that one had to go through. This kind of cost was referred to while discussing the desire and experience of cure, relief/ or non-relief.

The dimension of cost was often referred to while discussing the cure for disease or relief from symptoms. It was, to some extent, a description that 'they have got that cure or relief from symptoms for that amount'. *Makhan's pneumonia could not be cured despite multiple visits to GPs from Kandhar and spending two to three thousand rupees. He got a cure from Marathwada child hospital after spending 12 thousand rupees. The family is paying back the debt to the money lender*. Experience of non-relief or partial relief from symptoms was considered a wastage of money on the entire treatment by many who could not get the cure or relief. Arvind tried the treatment for his psoriasis for almost two years from Dr. Sujeet Deshmukh, a skin specialist. He spent around 4 thousand rupees for consultation, additional medicines and travel. There was no relief from the symptoms. He did not even know the cause of the disease and its prognosis. After that, he stopped taking treatment and thought that it was a waste of money, time, and energy.

The price tag of relief was a major impediment for many. After trying out many providers unsuccessfully they have given up pursuing the dream of relief and are living with suffering. While others like *Pitamber are in hope, remembering a statement from the doctor; he believes that he will get relief from paresis in his limbs due to spondylitis if he gets surgery (with a scope and camera) from a specialist doctor (he had heard about it on the Radio). He has identified the doctor and saved 25 thousand in the last couple of years to pursue relief from his suffering.*

Those who could afford it expected this cure with some dignity and respect. They expressed that they won't mind paying for the treatment offered with dignity and respect.

Kisan was admitted to a private paediatric hospital for five days at Nanded. Her baby was first assessed by Dr. Balikar. Later he was investigated for some blood tests and an X-ray chest. They were told that there was an accumulation of cough in the baby's chest and swelling in the baby's lungs. The baby was given injectable medicines for fifteen days. ***On asking about the experience of the hospital, she told that it was good as her baby got well.*** *Kisan's uncle said that even if they have to spend a little extra, it is very important that the doctor talks to them satisfactorily and the patient gets better from the ailment. He said "****we will buy medicines from outside if doctors want, but a doctor should talk satisfactorily and cure the ailment****.'*

The nature of illness also affected the pursuance of the desire for cure and relief. For minor illness or illnesses which were not debilitating, painful, and life-threatening (ill health that one can live with), other considerations like self-respect and dignity were important for them. Ujala further told that she was very sensitive in nature. She told me that if somebody insults or makes a demeaning remark or behaves inappropriately with her, she gets tense and loses her temper. ***The chances of getting shouted at, scolded, insulted, or looked down upon are very high at the hand of the doctor, nurse, and other paramedical workers at the government hospital. So, to avoid insensitive, inhuman, and undignified treatment she avoids government hospitals. She said that even government hospitals are also going to give a few tablets and not some elixir of life (Amrit) or gold, so why get insulted for those tablets if one can get similar tablets at private clinics afterpaying some money? One will lose some money only in getting treatment at private clinics.***

Relative importance given to cure and other experiential aspects in the care process differed when the illness was perceived as serious. When the cure is offered for serious conditions, especially through complex skilful interventions like surgery or with the use of some advanced technology, then the cure was valued. There was accommodative forgiveness towards other inconveniences that they had to go through or the unfriendly behaviour of busy and overworked health workers in the hospital. *On asking him about his overall experience with the government hospital services* ***Bishan told that overall it was a good experience, despite many limitations in the service provided and despite the experience of losing some money and jewellery in theft while he was sleeping on pavement/ footpath on the road as an attendant of the female patient, as well as other hardships that he had to endure of living for a long time without any support***

in and around the hospital. *He told that if somebody asks his opinion on seeking care for some illness, then* ***he would suggest a government hospital***. *When asked about the long duration of time they had to spend to get that care, he replied that if the condition of the patient was such and needed time, as satisfactorily explained to them by the doctors, then there was no point in rushing things unnecessarily.* ***They did not mind waiting because they had developed confidence in the doctor's effort, as seen from her nearly complete symptomatic relief from the condition on earlier occasions. The wait ended with satisfactory results in terms of a complete cure for the condition.***

The cure or relief from symptoms is usually an outcome of treatment and is seen towards the end of treatment. For ongoing treatment, partial relief from suffering or progression of illness and recovery, as predicted by the doctor, is seen as a marker of good treatment. Asaya, after emergency management of her snake bite from the government hospital, was taking treatment for post-bite ulcers on her entire feet and leg from a traditional healer in a nearby village. ***On being asked about the improvement in her condition she said that there was an improvement in her condition and that she was satisfied with the treatment she was receiving. She told that she used to do routine work in-house initially after her discharge from the hospital, as her foot did not bother her though there was a large black patch (her feet had lost sensation and become numb after the snake bite). However, after one to one and a half weeks' treatment, she now has started regaining sensation in her foot, as predicted by the herbalist, and now she cannot work as she used to because of pain. So, it was a sign for them of improvement in her condition. The ulcer also has dried up. They were happy because there was an improvement in her condition without spending much money when compared to what was suggested by Dr. Shende.***

The expenses he had to incur for this treatment consisted only of travelling cost which was around 120 Rs per trip (to and fro), for two persons. Recollecting their experience with Dr. Shende she told that he had charged them 100 Rs to tell them that she would need treatment at Nanded and will have to go there, all he suggested was one name of a private hospital doctor in Nanded.

5.2.1 Cure and care

Many health conditions do not have a complete cure. Management of some illnesses is a lifelong process. In the absence of a complete cure, the nature and degree of relief offered become an important consideration in evaluating the treatment experience. Improvement in some aspects of well-being, like relief from pain or suffering, and restoration of some function or structure, also serves as an important consideration in evaluating the care experience. *With many suggestions from friends and relatives, Shambhu visited the Government ayurvedic medical college and Hospital at District Headquarters in Nanded. Here he was admitted for almost two months. During the hospital's two-month stay, he got ayurvedic treatment, which consisted of some Ayurvedic medicines, mainly different types of massages and kinds of hot fomentation using different herbs and oils, etc.* ***In this government hospital, he felt he was cared for as he was getting personalized care.*** *Doctors and other hospital staff were talking to him, spending some time with him, and helping him in doing his exercises. There was some professional masseurs available, though they were not hospital staff and had to be paid for from one's own pocket. They were allowed to massage a patient with different kinds of musculoskeletal disorders and paralysis.* ***These massage sessions have a great deal of importance in his whole experience of illness and treatment, where he felt that he was cared for and somebody was investing time, energy, and skill to get him better.*** *He was told about the importance of massages and exercises. He had already developed contractures in his palms, elbows, and foot. There was wasting os muscles in the hand and lower limbs.* ***With the massages and herbal hot fomentation, there was an improvement in his condition, his contractures showed some relief and with more power in his both limbs, he could stand with support.*** *Among all the doctors he had taken treatment from, he preferred and liked doctors from the government ayurvedic medical college hospital and as an institution also he liked the ayurvedic hospital. The reason, as given by him for this, was that his condition improved there, though not completely cured.*

The genuine effort and sincerity of the care provider do not go unappreciated even if the cure is not achieved. *Pitamber was admitted to ayurvedic college for two months for the weakness in his limbs due to cervical spondylitis. He was given treatment with ayurvedic medicines, massages, steam, etc. he was well looked after for these two months during hospitalization; however, there was no improvement in the weakness of his limbs. Doctors made their efforts, but those efforts*

did not bear the fruit of recovery. He was appreciative of the effort but sad at the same time for no relief from symptoms.

5.3 Comprehensive treatment of all illnesses and restoration of health

The period of Illness, with its suffering, is a very difficult phase in an individual's life. The care-seeking journey with its challenges also contributes to this suffering, especially if the experience of seeking care is poor. For individuals with multiple co-morbidities, this becomes even more challenging. In the era of specialized medicine, the care-seeking journey of identifying relevant specialization and specialist providers has become a very fraught journey.

Specializations have led to a compartmentalized approach to body, illnesses and treatment among healthcare providers. When specialists provide these services in a commercial arrangement, then there is a possibility of the treatment being partial and incomplete with a focus only on a problem relevant to their own specialization. Care seeking for multiple morbidities requiring different specialists from a market setting (with different specialist having their own set-up) is a tedious task for a patient with a constant fear in their mind for the scope of errors, especially if there is no dialogue among the health care providers.

For patients negotiating with different specialists and managing their advice, is a tiring task. The absence of wholesome/ comprehensive care increases the possibility of continual suffering for the patient. *Asaya also shared the experience of her neighbour a* ***young boy who had post epileptic fall and head injury and developed hemiplegia. He was admitted to Dr RajAdhav's (Neurosurgeon) Hospital, they also had a very bad experience in that hospital. After a few weeks of treatment when the parents realized that there was no improvement in his condition and he had paralysis they asked the doctor about the paralysis of the body; the doctor replied that he was a specialist of the brain and he was treating his head injury, so he was not answerable to paralysis in limbs. They had spent a huge amount of money (2 lakhs rupees) and sold their land to pay the bill of patients.*** **During the course of treatment and after discharge, there was no advice from the doctor for physiotherapy and speech therapy, not even the suggestion for doing massage and movement of limbs which had resulted in contractures in his limbs. He lives with residual paralysis, contracture, and speech abnormality.**

The experience of diagnosis and treatment of multiple morbidities in a comprehensive manner to restore health without having to search for different specialists (and explain the nature of the problem or incidental findings of abnormality in blood tests or radiological tests) was remembered by Mayabai and her family as a good experience. Mayabai was suffering from mouth ulcers, nausea, vomiting, pain in the abdomen, and loss of appetite for a long time. She had taken treatment from many private practitioners, but there was no relief. The private hospital of Dr Bawadekar, with a USG examination, identified a gallstone and suggested surgery. The cost of that operation was beyond their reach. So, they decided to go to a government medical college and district hospital. *In the district hospital they got the papers for* ***surgery OPD*** *and was seen by Dr Ghosikar. They showed her previous papers, including USG reports. By this time, she had become quite weak. She was admitted to the hospital and had to undergo a* ***battery of tests****. Along with routine tests, she was subjected to* ***ECG and USG abdomen*** *as can be perceived from her interview. After going through the initial test results, the doctors told her that she had gallstones. In the investigations done for* ***anaesthesia fitness****, it was recognized that she had some problems with her heart. Due to this condition, she could not be operated. The doctors in the hospital, after a thorough examination advised her that she should take some* ***prescribed medicines from the hospital for her heart ailment that was identified in the check-up****. She was advised to come back after one month (she will be then fit for anaesthesia). If her condition is better next time, then she could undergo the operation. Bishan then requested the doctors to do something about her burning pain in the abdomen, loose motions, and mouth ulcers because those were her pressing concerns and taking her home without treating these conditions was amounting to keeping her in pain and suffering. He told them that she cannot eat properly; she is weak and was having giddiness due to the weakness. Then the doctors subjected her to another set of procedures. As can be perceived from the interview it was most likely* ***an endoscopy****. She was given* ***treatment in the hospital for her symptoms and suffering and was discharged after almost 12 days of hospitalization****. She could eat, her burning pain had significantly reduced, her giddiness had subsided, and* ***she was feeling much better****. With much improvement in her condition after* ***discharge****, she completed a total* ***of one month of medical treatment at home****. After one month, they decided to go to Nanded again, as advised by the doctor at the district hospital, for a further opinion about her heart condition and the treatment consisting of an operation involving the removal of her gallbladder containing gallstones.*

*She was **admitted again to the hospital on a subsequent visit** and was yet again subjected to a battery of tests for ascertaining the condition of her gallbladder and gallstones. She was **subjected to investigations again to ascertain her medical fitness for anaesthesia and surgery.** After confirming that she was previously detected with a heart condition, and was not in an imminent danger for surgery, they decided to operate on her for **the removal of her gallbladder. The operation was done** by Dr Potewar, a senior surgeon and head of the unit in the surgery department at the government medical college. **The operation went on well**, and she was shifted to the in-patient wards and admitted there for **post-operative care** for some days. The total duration of the stay in the hospital was about 15 days.*

Comprehensiveness is not only limited to having a different specialist opinion and integrating/ synchronizing/rationalizing the treatment from all specialists. The comprehensiveness of all healthcare-related services is to give a wholesome care experience so that the patients' interface with the institution becomes a comfortable experience. *Tanaji agreed and echoed that the government hospitals are dirty and overcrowded, but he still considered and rated the government hospital better than all the private hospitals in Nanded. He said that the reason for saying so was that the kind of facilities and services available and provided by the government district hospital could not be matched by any of the private hospitals. He said that the dirty and overcrowded government hospitals are some of the important reasons for a number of people seeking care in private hospital. He added that the treatment cost in government hospitals is negligible compared to private hospitals. He said that the **number of diagnostic modalities and treatment facilities available in the government hospital as one institute could not be matched by any of the private hospitals**. (*Most of the private hospitals provide very specialized care in the individual speciality; some of the hospitals have started with a combination of some specialization. However, none of the private hospitals provided the **kind of varied specialization with a number of experts in individual spatiality** available in the government hospital. The **necessary investigation facilities of all kinds are also available within one institute** in government the hospital, whereas very few private hospitals have diagnostic modalities available. Some private hospitals tend to have, if any, one or two diagnostic modalities needed for their specialization within one institute. So, patients most likely have to go to other private hospitals or diagnostic centres also for some diagnosis or opinion. In government hospitals, **the in-house availability of different specialists makes it easier to have opinions**

and consultations about related disease conditions of the patient. The availability of different diagnostic modalities and experts makes it easier in due course of time, the co-existing morbidities are treated, and complications can be avoided and handled with efficiency, if any arise, during the course of treatment. In government hospitals, most medicines are available and provided from within, whereas in private, everything is required to be purchased from outside. T**he materials like cotton, gauze piece, IV sets, gloves, spirit swabs, syringes** etc., also have to be bought from the market in the private hospital. *So the sheer size and number of doctors; and different specialists in the government hospital make it an institution where it is possible to provide effective and wholesome care to the patient, unlike private hospitals.*

5.3.1 Non-medical support services

Government hospitals provide very important non-medical support services, which makes it a caring service as against the medical curative services provided in the private hospital. ***These non-medical services include the provision of linen, clean bed sheets, support manpower, transport for referral and, most importantly the provision of food from the hospital****. Provision of food from the hospital is like sharing and taking away a huge responsibility of the attendant. It takes the whole treatment experience at a different level, specifically for those who are coming from far away rural areas. If the patient is from a really poor socio-economic condition, this becomes crucial support to the patient's family.* Even those who can afford to bear the costs, struggling, investing time and energy in arranging the food for the patient, along with arranging different treatment requirements in the precarious condition, with little knowledge about the dietary requirements of the hospitalized patient, in a new context and city makes the whole experience the worst nightmare for treatment.

Lack of comprehensive treatment even from a hospital has its own implications. Patients' interpretation of the treatment received and residual illness, even after visiting a hospital (especially a tertiary hospital) has wide possibilities. Speciality-specific treatment by a specialist doctor might finish his task of providing care, but that does not finish the care-seeking journey of the patient. This care-seeking journey continues and can possibly go in a different direction, including the wrong direction, like taking unscientific and risky treatment. Asaya's care-seeking journey highlights the consequences of a tertiary hospital's lack of comprehensive treatment. The

doctors at casualty in the government medical college and district hospital saw Asaya. *After going through the referral slip from CHC Mukhed and examining the condition of the patient, she was admitted to the hospital.* ***She was started on IV medicines and fluids from the government medical college hospital and was admitted here for four days. Her blood tests were done daily. Her condition improved, and her life was saved. She was referred to OPD no. 64, most probable surgery or skin OPD. The doctors in OPD 64, after observing her condition, had prescribed her some medicines to be taken orally. Doctors told them that her swelling would subside with medicine, and the discoloured patch will resolve slowly (this untreated gangrenous patch was left untreated or left to be treated on follow-up visits. This would mean no further treatment for the patient, especially a woman patient living 70 km away from the DH hospital this would mean no further treatment). The doctor in OPD 64 had advised her to come for a follow-up visit after a week to assess her condition and for further treatment. On the day before discharge, her blood was tested three times.*** *She recollected her memory and said that they used to test the blood also by pricking her fingers. (They might be doing it to check her bleeding time and clotting time.) Doctors told them that her blood reports were normal and there was nothing to worry about the effect of the poison.* ***She was discharged from the hospital on the fourth day of her admission. With discharge she was given some medicines to be taken orally.*** *She took medicine for the next week as suggested by the doctors at the government hospital. Oedema and swelling over the foot subsided in a few days. She was feeling better; however, the skin over the ankle region was black and without any sensation. Many people and the relatives who came to visit her advised them to go doctor again and show up. She, her family and most visitors believed that it was a miracle that she was alive after the large bite by a very poisonous snake, a cobra. Most of the visitors and village people, after seeing the site of the snake bite, told them that they should visit the doctor again as they believed that after the effect of the medicines is over there was a chance of deterioration of her condition. They told them that there was a chance that some poison must have still left in the body and would affect her after the effect of the medicines given wanes off. Four days after discharge, the fluid started appearing and accumulating in the affected skin over the ankle joint. Over the next few days, the area became a little soft, with a few blisters filled with fluid.*

Despite having good experience and support mechanisms at the government medical college and district hospital they decided to go to Dr Shende's clinic for his opinion and further treatment.

While deliberation it seemed that many considerations and issues affected and resulted in this choice. ***She got the best possible treatment for a life-threatening medical emergency when everyone swung into action, and she got a quick and best treatment in an effort to save her life. She got out of the precarious life-threatening situation. She had a residual wound with dead tissue on her foot. She was referred to the concerned department, where the doctor told her that she would get better and the residual lesion would resolve on its own and with the medicines that they had prescribed. However, the residual lesion did not resolve despite taking medicines regularly; on the contrary, it started worsening.*** *(*Thinking retrospectively; ideally, **she should not have been advised discharge before completely recovering** the wound from the government hospital. It is possible that there was, to some extent, a careless attitude or inappropriate judgment on the part of the doctor in OPD 64.*)* ***They, on the suggestion of different people, started believing about the possibility of residual poison in her body, which would have started affecting her after the effect of medicine provided by the government hospital wanes off. So, they needed a second opinion so they had to go somewhere other than the government hospital. The best possible option for them was the famous doctor in the adjacent block, whom they had earlier also tried to consult, Dr Shende. Many of their relatives and visitors had also advised them to go and show it to Dr Shende.*** *So, there was social pressure to go to have an opinion and treatment from a private hospital specifically at the private hospital of the famous Dr Shende. They felt that now her condition was not life-threatening and would have needed a long treatment procedure, and they were not sure about getting a similar treatment experience of promptness this time. They thought that now she was out of a dangerous, life-threatening condition, so she would need some advice and treatment with few medicines. They thought that they would get an expert opinion on now controlled conditions and take treatment for residual injury by spending a small amount of money. Based on all these considerations, they went to Dr Shende's private hospital for advice and further treatment. With the experience of Dr Shende's hospital, he now told that poor persons should not even keep their feet on the steps of his hospital. They did not anticipate that Dr Shende's treatment option would be so expensive. He told that it was a very expensive hospital. She added that if somebody is going to seek care at that hospital, he/she has to be ready to sell off their homes and lands. They thought that if they had visited the government hospital, doctors would not have advised the operation, at least without trying out medical management. Later she opted*

for treatment from a local traditional healer known for treating snake bites and post-bite wounds using some herbs.

5.4 Counselling

The value and importance of satisfactory information on the nature of illness and the nature of the treatment given in shaping their experience of satisfaction with services are briefly discussed in the section above. In addition to information about the nature of the illness, the nature of the treatment given and how that treatment would work, other information and counselling during the care process were also considered important by people.

Adequate time given by the doctor (to understand the patient's problem by listening to what the patient has to say carefully and asking some questions to understand the nature of the problem), explaining the nature of the treatment given, how medicines are to be taken, the precautions to be taken during treatment, possible side effects, disease aggravating or relieving factors etc.) was reported as an important reason for going to a private provider. The time given for satisfactory information and counselling was considered as valuable as medicines and served as the reason for spending money despite poverty on the consultation from private-sector doctors. *Sumangal told that even if they have to spend a little extra, it is very important that the doctor talks to them satisfactorily and the patient gets better from the ailment. He told, "we will buy medicines from outside if doctors want, but* ***a doctor should talk satisfactorily and cure the ailment.*** *In a* ***government hospital expenditure is less, but nobody talks in a satisfactory and humane manner."*** *Then she added that the PHC has a stock of medicines, but the hospital staff never spoke to her in a satisfactory manner and gave her medicines. They (doctors and other hospital staff)* ***neither explain to them anything about the medicines, the purpose of the medicine, estimated cost, or where to bring it from,*** *nor do they administer the bought medicine to the patient immediately.* ***If relatives or the attendant, ask the hospital staff about some concerns and doubts, then they are not answered or explained properly. In fact, the chances of getting rude answers are more, and after that, they feel insulted and then avoid talking to these staff members, usually sisters****. Whereas* ***in private clinics the doctor examines them properly,*** *writes the prescriptions and* ***explains to them where to bring the medicines from, the probable costs, and sometimes the purpose of the medicines used****. They even administer these medicines without any delay.* ***If a patient or the attendants ask them about their concerns and doubts,***

even sometimes repeatedly, then they are responded to in a satisfactory manner. *The doctors or hospital attend to the patient whenever requested without delay.*

On the other hand, a doctor from a government hospital, w*hile narrating his experience Keshram* (many respondents echoed this) told *that very few doctors* ***gave proper time to inquire the patient about his / her problem and thoroughly examining the patient****. He told that only the first doctor he had shown in surgery OPD had given him proper time for inquiring and examining. He also spoke to him nicely.* ***None of the doctors he showed in his subsequent visits, or as he has observed for another patient too, gave proper time for inquiring and examining the patient. Most of the doctors were in hurry to get rid of the patients as quickly as possible***.

Community members acknowledged that the critical element for a cure and getting relief from symptoms is the medicine prescribed by a doctor with his scientific knowledge. They were aware of the fact that they could not judge a doctor as good or bad only based on his communication skills. However, they also highlighted the importance of counselling and satisfactory dialogue. *When asked whether the doctor in private hospital or clinics are good then, he said all that he knows is that doctors in private examine them properly, talks to them satisfactorily, and gives medicines without delay so they prefer private. Even if a patient goes repeatedly every time, he/she is answered and attended to satisfactorily.* ***One member added that half of the illness gets better if the doctors talk satisfactorily***.

Inadequate counselling and unsatisfactory dialogue were a matter of concern for the patient and many time was reported even in private hospital consultations. *Last year they migrated out, during the lean agricultural season, to Pune in search of work. They stayed there for 4 months. While they were in Pune, she consulted one private medical college and trust hospital, popularly known as Jawale hospital and one more private hospital. Jawale hospital is a big multi-speciality trust hospital in Pune. She was shown in gynaecology OPD in the Jawale hospital for complaints of heavy bleeding during the menses and white discharge along with her chronic burning micturition. She was advised to do USG abdomen and pelvis along with blood and urine tests here. She was charged 800 Rupees for the blood tests. She visited the hospital again with the USG report.* ***The doctor advised her that she would need a hysterectomy. The charges for the operation as told to her were about 17-18,000 Rs. The doctor did not tell the conditionof***

the disease needing an operation, i.e., diagnosis was not given or explained to the patient. She was only told that she would need an operation, and the charges for the operation were given. *They spent 1500 Rs. for this advice from the Jawale hospital in Pune. As they did not have that huge amount of money to spend on the operation, they could not think of getting the operation done. Earlier, Dr. Trishila (Gynaecologist) by doing a USG examination, had told her she has a mass (fibroid) in her uterus and needed a hysterectomy. Therefore, she was under the impression of that condition. However, two USG reports available, one from Jawale Hospital, had recorded that her uterus was normal in size, shape and position.* ***The available two USG reports had recorded one small renal calculus. The patient was not informed about this finding. She was not advised about consulting another doctor for the problem with the USG report. She was not even given simple advice about increasing her water intake. On the other hand, she has advised a hysterectomy.*** **Even while advising a major surgery like a hysterectomy, the indication and reasons for doing the operation were not explained to the patient.** This can be either due to a blinkered specialist approach where the gynaecologist doesnot want to engage with the problem of another system of medicine or for the fear of losing a patient with a potential high-revenue surgical procedure to another doctor. However, such a biased way of revealing and hiding diagnostic findings from the patient has implications for the well-being of the patient. The following example of Asaya and Shambhu will discuss this in more detail.

The consultation session and information shared have implications not only for the psycho-social and economic well-being of the patient but, sometimes, also for the physical well-being of the patient. The advice can be about precautions to be taken, dietary intake, risk factors, danger signs and self-care components for maximizing health benefits to the patient. Sometimes there is a casual mention of some universal health advice but discussing specific advice specifically in relation to the disease and its benefits for recovery and avoiding complications has its own value. *Shambhu recalls his whole experience with hospitals at all levels viz. sub-district hospitals, multi-speciality private hospitals, district hospitals with UG and PG medical colleges and apex hospital at the state capital Mumbai also having UG, PG, super speciality and allied medical training facilities including physiotherapy and was wondering* ***if he was told about the exercises and massages, he would have got better much earlier without developing contractures.*** *He is very hurt and lost hope in medical professionals with the fact that none of the*

doctors from the allopathic system of medicine both in private and government ranging from the sub-district level to the apex hospital in the capital city gave him simple and crucial advice on exercise and massage. By pointing out his contractures and wasted limbs he says it could have been avoided. He recollects ***the advice given at KEM hospital in Mumbai and says that by following the instruction his family members and he himself made sure that the waterbed is constantly shaken and he did not have any bed sore in the first year of his illness***. *By narrating this he is trying to articulate that he is very compliant patient and sincere in following the doctor's instructions.* Therefore, the specificity of advice and emphasis was given to explain the seriousness of it was valued by patients as it gave them a feeling for cared for by a doctor and displayed the doctor's sincerity in the recovery of the patient.

In addition to the specificity of the advice given the objective with which this advice is given also mattered to the patient. In the larger atmosphere of rising unnecessary medical interventions and cut practice among medical professionals, patients have their own way of evaluating the advice given especially for its objective. The detailed consultation and information given by two different healthcare providers for the same health condition meant different experiences and were evaluated differently by Asaya.

After lifesaving treatment for a snakebite from a government hospital, one day they decided to go to Dr Shende's hospital for his opinion and further treatment on post snake bite gangrenous feet of Asaya. Doctor asked them about the complete history of events. He asked them to describe the snake. He asked them about any history of bleeding from the mouth, gums, blood in vomiting and in cough, in urine, and in stools, or from any other site. He examined the site of the bite. He told them that she was bit by a Parad, a local name for a snake type. They believed that she was bit by a Nag that to a cobra. So there was a disagreement between doctor's opinions and what they thought about the type of snake. ***While commenting on their apprehension of the residual poison left in the body and the possibility of its effect doctor told them that there was no poison left in her body. However, he further added that her condition specifically of her foot was serious and told them that it would need immediate attention. He advised them to go and visit one doctor in Nanded. He gave them his address. He told them that the doctor in Nanded would operate on her foot. After the operation, he told them that she would need frequent changes in the wound dressing. Those dressing would be done at Dr Shende's hospital. This***

treatment, as told him would cost them around 25,000 Rs. He told them that if this treatment does not help in getting the wound healed, then she will need a different operation at Nanded where the doctor will put skin from her thighs on her wound. The follow-up visits and wound dressing then can be done in his hospital at Mukhed. He further told them that if the thigh skin also does not help in healing the wound then she will have to undergo amputation of her foot*. He told them to go immediately to Nanded and visit the doctor he has suggested. He told them that if they don't have money with them right now then they can go tomorrow.* ***He cautioned them not to get late. (Was it a scare tactic? Or was this sound advice?) He told them to call him back on mobile when they reach the doctor suggested by him at Nanded (Asaya and Madhukar suspected cut practice and financial kickbacks).*** *He prescribed them some medicines to be taken orally. They paid the 100 Rs consultation charges and came out. They got scared with the battery and string of operations he suggested to them.* If one were to assess the information given by Dr Shende, it is detailed information given along with prognosis and possible interventions at each stage. He rightly told them about the seriousness of the condition too. However, this counselling and detailed information scared them off.

After hearing this advice and thinking about their own economic condition where they could not afford to go by the advice given by Dr Shende and there was amputation there as one of the possible interventions. They decided to give it try by visiting the herbalist person in a nearby village, as told to them by some people in OPD. They reached the house of the herbalist in the village. He told them to first visit the local temple of Hanuman and offer prayer and one coconut before starting the treatment procedure. He told them that he won't charge anything them for the whole of the treatment; however, at the end of treatment if they are satisfied with the success of the treatment then they can offer anything to the temple of Hanuman as per their economic capacity without telling him anything about the offerings. As told they went to the Hanuman temple, offered prayers and broke one coconut in front of the temple. They went back to him. He asked them about the history of events and the description of the snake. They told him whatever happened before and after the snake bite, including the history of treatment taken by the government hospital and advice given by Dr Shende. Meanwhile, he took out one photo album to show them. He then showed many pictures of snake bite patients who have taken treatment from him. The album contained a picture of the bite site before starting the treatment and at the end of completing the treatment. The photographs had the addresses of those persons written on them.

They saw many pictures of varied levels of affliction after a snake bite. Some of the pictures contained larger wounds and more area affected than what she had. In most cases, the wound had healed completely at the end of treatment. This album gave them some confidence and served as evidence of this person's ability to treat her. He then examined the site of the bite where the skin over the region of her ankle had turned into a large discoloured, almost black anaesthetic patch. He touched and pressed over the affected area. As it was completely senseless, so it did not affect her much. He then brought out some sharp objects and started to dig into the affected skin over the numb (anaesthetic) foot. The whole area now turned into a large ulcer covering most of the dorsal side of the foot, till the lateral edges of the sole, and a few inches above the ankle joint. He then told them that he will give them some herbal medicine to apply on the site. He then told them that she will start getting sensations in the affected area after one to one and half weeks' treatment. He then took a wooden piece, most probably a root or stalk of some plant, and rubbed it on a stone with a small amount of water added to it while rubbing it on the stone. He then applied the resultant paste formed on the affected area.

After a few weeks of treatment, ***one prognosis was that she will develop a sensation in her feet after a week's treatment as told by the herbalist person so their trust and confidence increased further. He had further told them that the wound will start developing crust from the margins and it has started appearing. He had also assured them that she will get well in 3-4 weeks of treatment from him. Madhukar further added that the herbalist had a very systematic way of treating patients, where he asks different questions before giving medicines and has different treatments for different snake bites. The herbalist had told them about different types of snake bites where one variable affects the brain and kidney with blood in urine and another variety where patients have difficulty in breathing and paralysis. He also told them that his treatment of snake bites, if given immediately, prevents the formation of wounds and ulcers. They told that the herbalist was a very nice person who was not after earning/making money; he does not take a penny from the patient, rather, being a devotee of God he tells his patients to offer whatever possible within their capacity if they are happy to the god.*** *However, Asaya and Madhukar further told that they won't trust him blindly and if his treatment does not give results if there are any complications, then they will go to the government hospital.* Thus, earnest advice, counselling and information given without any financial motives with the patient's best interest in mind (as felt by the patient) were reported as better counselling and care experience.

In the case of chronic illnesses or illnesses requiring long-term treatment or lifelong treatment adequate counselling and satisfactory information sharing is very important. A patient's search for a complete cure or final cure or complete relief from symptoms is a very agonizing experience, especially in the context of long-term illnesses. Adequate counselling of patients on accepting the nature of the illness, and how to deal with or live with chronic disease is very important; in the absence of such information, the patient is in search of a better doctor or health care provider with many uncertainties in mind about the prognosis of illness, effectiveness of treatment or their own efforts in resolving the problem. It is important to convey limitations of personal or professional capacity including inadequacies of scientific knowledge in dealing with the health condition that is being treated so that patients and family members (especially in the case of child patients) are able to cope with it in a better manner. *They (the Anmol family) are unclear about the future course of action as they have taken treatment from a range of doctors and providers ranging from many specialists at district headquarter, to private qualified and unqualified medical practitioners in the block town. They have also visited many practitioners of alternative systems of medicine ranging from district ayurvedic medical colleges and hospitals to many familial herbal remedies practitioners. They also have resorted to folk as well as faith healers. Whether this is doctor shopping? Don't they trust their treatment providers? As explained earlier they trusted most of their treatment providers and were told that most of them gave them temporary symptomatic relief with medicine, but the condition reappeared after stopping the medicines.* ***Most of the treatment providers completed the said duration of treatment and stopped the medicines after completing the doctor's treatment for the prescribed duration. Many specialists have made many follow-up visits and have completed treatment given during these visits. The doctor is changed after sufficiently trying him out or in circumstances where he is not available or accessible at a given time. None of the doctors has given them any definitive or probable diagnosis, and none of them explained to them the prognosis or the total duration of treatment required if it is a long-term treatment so that they will try that treatment. Anmol's mother told that doctors if with some confidence tell them that it is a long-term treatment for a specific number of years then they will try that treatment without searching for other alternative treatment options. This whole experience of running to different doctors was quite tiring and frustrating. None of them even the orthopaedic and other specialists was gracious enough to accept their limitations in diagnosing the case and***

referring them to an appropriate specialist like a rheumatologist or some other socialist as they consider appropriate after trying out their treatment. If they asked why the treatment prescribed had not worked and showed any discontent or doubts over the treatment, then the doctors retorted back, saying that they are not the son of the gods, so they cannot guarantee them to cure.

Proper counselling and adequate information give a sense of satisfaction. In absence of adequate information living with a dilemma and many possibilities of actions that could be done or could have been done is a very difficult feeling for patients or attendants to live with. *Ranpat's uncle had swelling on his neck. He was shown in a private hospital at Nanded. They did some investigation, including the FNAC test, suggestive of the interaction with Ranpat.* ***The doctor had informed them that the swelling was of cancer and needs an operation. The doctor informed them that cost of the operation was around 15,000 Rs. He assured complete cure for the disease. They decided to get it operated from that hospital. He was operated there and was admitted for some days. The total hospital bill was 55,000 Rs. They had spent on medicines and other consumables separately and there was an additional cost of living and food for patients and attendants. They did not anticipate so much cost when the decision to get it operated on at that private hospital. They had to sell off some of their lands to pay the hospital bill. Within a month of the operation, the patient developed multiple nodules at the site of the operation. The patient died within two months. They feel that doctor did not give them proper advice and treatment. They feel that if the case was beyond their management, the doctor should have referred it to the appropriate centre. Despite spending so much money the patient lost his life. They keep wondering what would have been the prognosis without the operation, or if they had visited some other hospital, at a higher level.*** This non-closure, at a psychological and emotional level, to the care-seeking experience was considered an undesirable and avoidable experience.

5.5 Experience with inter-personal interaction in the care process

This whole chapter is discussing the dimensions of quality as perceived at the level of the interface of a patient with the doctor during the care-seeking journey. Therefore, this entire chapter with all its previous sections is about the interpersonal interaction between doctor and patient. However, beyond the technical content of medical interventions comprising assessment

of health status and intervening to improve health condition, it is important to understand psychological and sociological aspects of the interaction as experienced by people while interacting with a doctor. This section will explore the psycho-social dimensions of the doctor-patient (attendant) interaction as experienced by the community.

The psychosocial dimensions operating at a personal level and relevant for the clinical/medical care level are discussed here while psycho-social aspects operating at the larger institutional level and invoking larger social structural factors and relevant for the health system are discussed in the subsequent chapter on sociological dimensions in care seeking.

The community also seemed to differentiate between this interaction's medical and psycho-social aspects. There were expectations from the community on both these aspects. While discussing their expectations and their idea of good quality services various factors were raised by Nanak More. *He told, along with the above two mentioned factors, the* ***issue of appropriate behaviour by the hospital staff with the patients and their attendants. This issue starts with giving appropriate time to examine the patient and take proper history. The doctor should understand the patient's concerns. The whole treatment process should be appropriate where patients are provided with information about the nature of the illness and possible treatment options. The doctor and other hospital staff should behave humanely and politely with the patient and the attendants. Most of the time, the treatment experience is like adding insult to injury.*** *Patients and their attendants should be treated in a dignified manner as the whole illness experience of pain and suffering and inability to do anything and dependence on powerful medical professionals makes them vulnerable as health and life are at stake.*

Being at receiving end of anger and shouting by doctors and other health workers was not a pleasant experience in seeking care. *Recollecting his experience in the lift and after observing* ***many patients being shouted at different places by either the doctors or nurses or by the other supporting staff, Keshram said that it was very important that hospital staff behaves humanely with the patients. He refused to enter the lift and had to climb down immediately after surgery (minor) of removing a small mass from his neck. He felt very bad about this insensitive behaviour.*** *Monabai added that doctors and other hospital staff* ***neither explain to them anything about the medicines, the purpose of the medicine, estimated cost, or where to***

bring it from *nor do they administer the bought medicine to the patient immediately.* ***If relatives or the attendant ask the hospital staff about some concerns and doubts, they are not answered or explained properly. In fact, the chances of getting rude answers are higher; after that, they feel insulted and avoid talking to these staff members, usually sisters***. The rude and insensitive behaviour of doctors and healthcare workers was not something anyone would like to go through. Vulnerability and suffering from illness make the experience of rude behaviour by doctors very painful.

The insensitivity and rude behaviour of doctors have crystallised very well by Kisan's *uncle who went on to say that* ***Doctors at government institutions don't have patience and manusaki i.e. human nature and skills to interact with patients and the attendants***. *Later he told that with the fixed salary per month, performance is not really a concern of* ***the government health professionals, so they don't really take efforts to treat patients. He further added that medical professionals of today's time are different from that of yester years in their attitude of manuski. There is a rapid deterioration of manuski among the doctors.*** This was not however exclusively in government hospitals only some patients reported being at receiving and of rude and insensitive behaviour of doctors even in private hospitals despite spending lakhs of rupees on care.

Government hospitals also had some doctors who made the experience of seeking care pleasant with their sensitive attitude, and gentle behaviour. While narrating the experience of interaction with the hospital staff (of the government medical college., Nanded) Mayabai told that the ***doctors were nice and had never shouted at her or other patients.*** *The doctors did regular rounds for check-ups and* ***they spoke politely with her and with other patients as well***. *However, the nurses were blamed for some rude behaviour, which has been discussed in the subsequent chapter.*

Experience of seeking care from the government ayurvedic medical college and its doctors and other hospital staff were reported by many respondents (experience of Bhagirath, Pitamber, and Shambhu has already been discussed) as being very caring, gentle and fondly remembered. ***Among all the doctors he had consulted Shambhu preferred and liked doctors from ayurvedic hospitals and as an institution also he liked ayurvedic hospital.*** *The reasons for*

this were that he improved here with the ayurvedic doctors though not completely cured. ***Doctors were considerate, and concerned, and were used to treating him as a person and talking to him, they had taken out time in their daily schedule to talk to the patient*** *and explain the nature of the illness, prognosis, and precautions to be taken after treatment****. The doctors and institution as a whole were in no hurry to get him out of the hospital, they were ready to keep him as an indoor patient for one more month till he improved significantly.*** *Whereas his experience in government the hospital was that it was very difficult to become an indoor patient. They had made him wait for a long time in the emergency OPD in SGSMC at Nanded and even at KEM hospital Mumbai. After many requests and through some known doctors they have managed to become a patient of the government hospital. However, in SGSMC Nanded he could not become an indoor patient of the hospital. After begging he was allowed to spend one night and was shown the gate early in the morning. Thus there was a tendency to take the patient out of the hospital premises as early as possible irrespective of whether the patient got relief from his symptoms or not. In his case, doctors did not show the curtsy of dressing his painful ulcer.*

In addition to sensitive, gentle, polite and humane behaviour, it was expected that doctors would give some confidence to the patient and relatives, so assurance of cure, and care at least of putting in sincere efforts to try and heal the patient. This made a lot of difference in evaluating their experience with that provider. These doctors were remembered as good doctors.

On the advice of Dr Adhav, Nayan decided to take the baby to the adjacent town of Loha to Dr Panwar. This town is 15 km from kandhar with good connectivity by road. The baby was taken to Dr Panwar's hospital and was admitted there. ***Before admission, Nayan had asked the doctor whether it was possible for him to treat and cure the baby with the given condition or else he will take the baby to Nanded, the district's headquarter for further treatment. (He was trying to get assurance from the doctor about treating the baby.) Dr Panwar assured of completely curing the baby and putting in all his efforts****. However, Dr Panwar told them that it will cost them more, and told them to be ready to spend more money.*

The experience of this interpersonal interaction is very important to patients, attendants and community members as this relates to how they are being treated as human beings. Any compromise on that and the feeling of being treated as subhuman is an insulting feeling. This is

one of the important reasons for avoiding care from government hospitals and for fights with doctors or hospital staff**.** ***Ujala*** *further told that she was very sensitive in nature. She told me that if somebody insults or makes a demeaning remark or behaves inappropriately with her then she gets tense and loses her temper. The chances of getting shouted at, scolded, insulted or looked down upon are very high at the hand of the doctor, nurses and other paramedical workers at the government hospital. So to avoid insensitive inhuman and undignified treatment she avoids the government hospital. She told that even the government hospital is also going to give a few tablets and not some elixir of life or gold, so why get insulted by those tablets if one can get similar tablets at private clinics on paying some money?*

The behaviour of a doctor decided if services from that institution will be accessed or not, therefore is very crucial at lower levels of health care institutions. *While discussing the changes in the functioning of the RH at Kandhar he again invoked the behaviour of the doctor as a proxy or important criterion for assessing the RH. He told that the current medical officer Dr Sugadekar as a good doctor. The reason he gave for sighting him as a good doctor originated sometime in the past when he had taken some of his relatives as a patient to him. During that experience, this doctor had spoken to them politely, satisfactorily and with respect. Their patient also got well with his treatment. Whenever he has to accompany a patient to Kandhar RH in case of emergency then he calls him on his mobile and tells him about the condition and their arrival. Then Dr Sugadekar usually comes to the hospital before them or else they will call him after reaching there, in that case, the doctor attends to them without improper delay. He speaks satisfactorily, explains their condition, asks for medicines from outside if needed and treats their patient or gives necessary advice in case of referral. He recalls and says, "if I or any other person from the village happened to meet Dr Sugadekar anywhere outside the hospital, he recognizes us, talks to us respectfully, enquires about us"*. Thus, Dr Sugadekar is known to them as a treating doctor, and medical officer of RH as well as a nice person beyond his professional capacity. This link and familiarity with him as a nice person with having humane nature i.e. manuski, helps them have faith in him easily, developing the relationship of mutual trust and faith. This is substantiated by his professional skills in relieving the suffering of the patient and giving proper advice in a satisfactory manner that people can understand. On further probing whether satisfactory and respectful talk of the doctor or proper treatment and relief from symptoms is prioritized then *he said that there are some doctors who don't talk much but do*

correctly that treatment, in that case, people visit such doctors only in that kind of need and avoid unnecessary talking to a doctor as they have confidence that their patient will get appropriate treatment and will get better. "If we see a doctor putting in some effort in examining, investigating and treating a patient then we don't disturb the doctor, it is only when our patient continues to suffer and the doctor does not even bother to attend to and do something then it raises doubts in our mind."

5.6 The integrity of the doctor

It was observed that during the care-seeking journey patients and attendants were assessing the doctor/health care providers on various parameters. While doctors were assessing patients for their health condition and giving treatment for illness on their judgment, patient and attendant were assessing the doctor for his sincerity, gentleness, confidence, earnestness, skills, efforts, promptness, caring attitude, etc. and making a judgment on continuing treatment or following the instructions given. The community's opinion about healthcare providers on these various parameters through their care-seeking experience is discussed below. Differential knowledge levels of doctors were also acknowledged and were evident in the qualification and experience that they have, there was not much attempt to evaluate doctors for their knowledge. It was usually assumed that if they are qualified doctors they will be knowledgeable, and beyond their capacity to evaluate them.

In addition to this assessment of professionals, there was constant reference or comment that doctors are increasingly running after money. Deterioration of professional ethics among medical professionals had become commonly held knowledge. There was repetition, from different respondents in interviews and group discussions, of comments like doctors, have become butchers, and doctors are acting like *Dalal* (middlemen) in the cow market. These comments show that patients and the community were judging doctors for his/her moral character and conduct, professional integrity, trustworthiness, truthfulness and credibility. Seeking the opinions of different doctors before a major medical decision like surgery, or invasive procedures were often reported and reflected the lack of trust in medical professionals. Cut practice and financial kickbacks among health care providers were sometimes mentioned by community members to question the motives of doctors in their practice.

The feeling of being cheated by a doctor in the care process to fleece them of money by doing unnecessary operations and procedures was commonly reported. The unnecessary and excessive prescription of medicines to earn money from the medical store was well known among people, and they tend to balance it by purchasing half of or some of the total medicines prescribed. They had to undergo unnecessary diagnostic tests. However, undergoing unnecessary (as they perceived) surgeries was a matter of serious concern for them as it meant a lot for their physical health and abilities for future life were at stake. Often mentioned common unnecessary surgeries (based on their community experience of an increasing number of people being operated on for these procedures) included appendectomy, hysterectomy, cholecystectomy and the most common being caesarean section. Caesarean section often raises doubt in their mind about the necessity or rationality and motive of a doctor. *After reaching the Padam hospital she was admitted there. The doctor took their history, examined her and told them that she had lost all her amniotic fluid and her condition was serious. (Patients and relatives are constantly kept under worst-case situations or made to believe that condition of the patient is serious so that possible complications can be attributed to the seriousness of the ailment and if the outcome is good then the doctor earns good respect and money. It's being raised here as she was given a trial labour of about almost 20-22 hours in this hospital.) Her relatives, parents and father-in-law, requested a doctor for trying out normal delivery. The doctor also promised them of doing normal delivery after examining the patient. She was given a trial of labour after her admission at around 4 am in the morning. Throughout the day she was in the hospital and was constantly examined and monitored.* ***Toward the end of the day, the parents and father-in-law of the Sulekha requested asked the doctor whether it was possible to do normal delivery, if normal delivery is not possible and there is a chance of doing a caesarean section then they would like to take the patient to the district hospital at Nanded for further treatment. They also requested the doctor to inform them about his decision by 10 pm, so that they can arrange for sulekha and their transport to the Nanded district hospital. It would have been difficult to arrange a vehicle after 10 pm at night. The doctor examined the patient again and promised them of doing normal delivery. After midnight at around 12.30 to 1.00 am doctor told them that she requires an operation and the choice was given to either get operated on there in the hospital or to shift the patient wherever they like. At this hour of the night there was not any option available in this new town for them but to get operated there, as no private vehicles were***

available in the market to shift the patient. *The doctor told me that normal delivery is not possible and CS is needed without even explaining the reasons for doing the same. They agreed to the operation and requested a doctor about the safety of the mother and the baby. She was operated upon early morning around 4 am. She delivered a baby boy. They believed if it was a government hospital then it would definitely have been a normal delivery.* ***They felt cheated because despite requesting the doctor did not inform them about his decision within time.*** They felt that caesarean section was not needed and even if required they would have preferred it to be done by the government hospital as that was affordable for them. Here, they felt that doctors cornered them into a situation of helplessness and exploited their vulnerability to earn more money by doing unnecessary surgery.

It is expected that in medical practice consent of the patient is taken for any invasive procedure and surgery. The consent given has to be honoured by the doctor. Healthcare procedures or providers should not be forced on the patient directly or indirectly. When a patient makes specific demand of avoiding a particular healthcare provider, based on his past experience and has doubts over his motives then it is important that this request is honoured by the doctor. However, there seemed to be a complete disregard for such a demand from the patient. Healthcare provider was imposed against their will.

Dr Adhav examined her (Sulekha) and told them that he will give it a try for normal delivery. Later in the evening, he told them that she will need a caesarean section. She was operated on with a caesarean section at around 9 pm. The price for a caesarean section was negotiated by the father-in-law and the doctor and was fixed to 13000 from 15000 as told earlier. The price was negotiated before the start of the operation. While negotiating the price father-in-law ***Nayan More had told Dr Adhav that he would either get her daughter-in-law operated on by Dr Adhav or prefer to transfer her to Nanded rather than getting her operated on By Dr Khure, the other gynaecologist in the town offering caesarean section services through another private hospital in the town*** *along with his paediatrician wife.* ***He had clearly told Dr Adhav that he has had a bad experience in the past with Dr Khure, where his niece had lost her baby in Dr Khure's hospital so he does not trust Dr Khure. He even had a fight with Dr Khure at that time****.*

Sulekha was taken up for the caesarean section in the night at around 8.30 pm. ***Dr Adhav was performing a caesarean section for the first time in his newly opened private hospital. Dr Adhav despite the knowledge of the feud and lack of trust of the family of the patient over Dr. Khure, called Dr Khure- both husband and wife****, them being the only gynaecologist and paediatrician available in the town, for their opinion and help if needed during the operation. Dr Khure had seen Nayan More, the father-in-law, of Sulekha.* ***Nayan thought that Dr Khure would harm the baby during the operation****. The caesarean section was done and the baby was delivered. The baby had meconium aspiration. The condition of the baby was not good so the baby needed hospitalization under a paediatrician. Doctors told them that baby needs to be kept in a glass cubicle (incubator). This facility was not available in Dr Adhav's hospital, as Dr Adhav was BAMS, CCH. The only facility available in the town was at Dr Khure's hospital.* ***Nayan and his family believed that Dr Khure had deliberately harmed the baby in order to settle the scores of fights they had in the past.*** *They also told that Dr Khure might have realized by now that this patient (from Nayan's family) who used to come to his hospital is not going to come to Dr Khure anymore. (This shows the trust deficit in the community about the behaviour of medical professionals. It also reflects the community's apprehensions, and the possibility of unethical behaviour by the medical professionals.) When the family was told about the meconium aspiration pneumonia and the condition of the baby they attributed it to the actions (acts of commission) of Dr Khure. The subsequent advice of Dr Adhav about getting the baby admitted to Dr Khure's hospital was not acceptable to Nayan and his family. He refused to get the baby admitted to Dr Khure's Hospital.* ***However, at this time of the night around 10 pm, there was no other option but to admit there, apart from shifting the baby to some other town. Dr Adhav and all his relatives requested about getting the baby admitted at least for that night in Dr Khure's hospital. He agreed to it and sent the baby along with the relatives and the father of the Sulekha to Dr Khure's Hospital.*** *Where the baby was admitted in a separate room meant for babies where all the babies were kept in an incubator. No one was allowed to stay in that room. The mother of the baby was receiving post-operative care in Dr Adhav's hospital. The night passes by. In the morning Nayan sent Sulekha's father to see the baby. Sulekha's father visited the baby and told them that baby was weak and was not showing any movements. Nayan sent another relative after some time to assess the condition of the baby. This time also the baby's condition was the same. So* ***Nayan along with another relative went to see the baby.***

They asked to take the baby out of the incubator on the pretext of taking the baby to breastfeed. The baby was brought out from the incubator by the ward attendant lady and was handed over to Nayan. This time the condition of the baby was poor, with no body movements. The mouth of the baby was dry. Baby could not even cry. Looking at this poor condition of the baby with no expectation from Dr Khure, given their past experience, they decided to take the baby away. Nayan told the attendant to call the doctor. At that time Dr Khure was not in town. He had gone to the adjacent town. However, his wife Dr Sanchita Khure who was the paediatrician was available in the hospital. She came to talk to the relatives of the baby after they had called her. She shouted at the relatives as they were asking for discharge to shift the baby giving the reason for negligence at their hospital. She shouted at them and told them that they were not humans, they were behaving like animals. She refused the discharge till Dr Khure comes back, as he was the main doctor of the hospital. Nayan and the accompanying relatives got angry with such behaviour of the doctor. They started fighting with Dr Sanchita. She refused to talk to the baby's attendants. She called her husband Dr Khure and went to her home.

After some times Dr ***Khure came back, and he assessed the baby. He told them that the condition of the baby was poor. There has been negligence of the baby from their side. After the operation at Dr Adhav's hospital and after doing work at their own hospital they were tired and they went off to sleep so they could not monitor the baby well.*** *He told them that he had seen the baby at 4 am in morning that time baby was well but somehow the condition of the baby worsened. He told them to take the baby to some other hospital as per their wish.* ***Then Nayan told him 'You have refused us discharge when we asked for it, now keep the baby admitted in your hospital but if something goes wrong with the baby then be ready for the consequences'. He had asked for the baby in the morning at 9 am and Dr Khure had told them to take the baby away at 1 pm. Before leaving the hospital told Dr Khure that he was ready to pay whatever it costs but won't take the baby until the baby was normal. (Whether this kind of confidence to hold the doctor to task and readiness to pay whatever the cost is charged can be shown by any other poor or lower caste person is questionable.) He along with his relatives left the hospital and went to Dr Adhav's hospital. Then one attendant from the Dr Khure's hospital came along with the baby behind them and he handed over the baby to them and the bill of 3000rs. They paid the bill to him and took the baby.*** Sulekha's experience raises the

question of the professional integrity of the operating surgeon who invited another doctor who the patient did not trust (because of his past experience) and had categorically told he would prefer going to another town but won't take treatment from that doctor. The consent given for surgery was for a particular doctor and this was not honoured. The initial refusal of discharge and later sending away the baby with staff both raise questions about professional practice.

While comparing Dr Adhav and Dr Khure they rated Dr Adhav better than Dr Khure. If one looks at their qualification and experience, then Dr Khure is highly qualified in terms of having an additional DNB degree. Both of them were DGO. Dr Khure was more qualified and was practising in the town for a longer period of time, at least by three years, as compared to Dr Adhav.

Infrastructure wise Dr Khure's hospital was more equipped, offering better paediatric services with qualified paediatricians being available in his hospital. Both of them performed these procedures at comparable rates. **Thus, every measurable factor is in favour of Dr Khure still Dr Adhav was preferred by this family.** ***The reason given for this was their past experience where Nayan's niece had lost her baby after 2 days of delivery in the same hospital.*** *Ranpat, Sulekha's husband, also* ***pointed to the unethical, immoral practice of extracting money by Dr. Khure by giving an example. He told that one of the women from Panshevadi*** *was taken to Dr. Khure for delivery in the recent past.* ***Dr Khure examined the pregnant woman and told her that she would need a caesarean section. The family, a wage labourer from a lower caste, could not afford the cost of the operation. Then decision was made to take her to the Government-run rural hospitals. Dr Sugadekar from RH Kandhar examined her and told them that she will be delivered normally in 20 minutes. She was delivered normally without any operation in 20 minutes in the RH Kandhar.*** Such experiences and numerous other accounts of normal deliveries done in a government hospital **or sometimes even in the transportation vehicle of the pregnant mother who was advised C-section from private hospitals were symbols of unethical and immoral practice by a doctor in the opinion of the community.**

Such malpractices with financial motives sometimes have serious and long-term consequences on the health of the patients (or patients assume so). Such malpractices are perceived as very

serious issues beyond the attempts of simple profiteering, as it harms the patient and sometimes lead to consequences that the patient has to bear for life. A doctor intentionally doing harm to the patient or contributing to the deterioration of his health is a serious breach of professional integrity. *Shambhu is agitated with the fact if he was having an ailment that doctors at apex hospital in Mumbai couldn't operate then why was he promised and advised an operation at Aksha hospital, to begin with, and was kept waiting for 3 days and was sent out without operation. He is curious to know the capability and experience of doctors at Aksha hospital in doing an operation on patients with an ailment like his, quadriplegia with a fracture at C3.4, 5 vertebras. He is still wondering if he had gotten proper advice and prompt necessary treatment would his condition have been different. His precious time was lost due to a lack of advice from a doctor at CHC and then was wasted by Aksha hospital initially promising and later refusing an operation that they don't have the capacity to do. He is very hurt and lost hope in a medical professional. He is sad with the fact that none of the doctors from the allopathic system of medicine both in private and government ranging from the sub-district level to the apex hospital in the capital city gave him simple and crucial advice on exercise and massage.*

Exploiting simple and non-suspecting patients' vulnerability with utter insensitivity towards human emotion was remembered by the community as the downfall of the spirit of humanity by the community. *Asaya shared the experience of a* ***young boy who had post epileptic fall and head injury and developed hemiplegia. He was admitted to Dr. Raj Adhav's (Neurosurgeon) Hospital. They had a very bad experience in that hospital. After a few weeks of treatment when the parents realized that there was no improvement in his condition and he had paralysis they asked the doctor about the paralysis of the body, the doctor replied that he was a specialist in the brain and he was treating his head injury, so he was not answerable to paralysis in limbs. They had spent a huge amount of money (2 lakhs) and sold their land to pay the bill patient.*** During the course of treatment and after discharge there was no advice from the doctor for the physiotherapist and speech therapist, not even the suggestion for doing massage and movement of limbs had resulted in contractures in his limbs. He lives with residual paralysis and contractures.

Moral character and ethical behaviour by a doctor can affect access to and utilization of health services, especially for women patients. *Both Sumangal and Kisan's mothers compared Dr*

Gedam with earlier doctors i.e. Dr Surwade and Dr Chahal and said that all the women in the village avoided the earlier doctors, and whenever Dr Gedam is on duty women make sure that they tell other women about his presence so that they will take treatment from him. So in the given infrastructural facility doctors with similar qualification or in fact, Dr. with a BAMS degree was chosen over a doctor with an MBBS degree because of their attitude and behaviour.

Commenting on declining respect for medical professionals overall *Vithoba More gave some examples to tell how doctors themselves were responsible for the decline of respect for the profession at large. He then linked it with medical education, recruitment policies, and rise of private medical colleges and overall change in the education system at large. He thought that the lack of respect for medical professionals is growing because more doctors are doing unethical practices to earn more money. He was linking this to the trend of an increasing number of private medical colleges and them admitting incompetent students for earning more money which in turn was producing incompetent doctors.*

5.7 Timely and convenient services

While discussing their care-seeking experience one important issue highlighted and preferred by most of them during their care-seeking journey was prompt services. Promptness of service delivery was one of the most common reasons cited for preferring private health care providers. Institutions providing quick services are preferred over institutions having time-consuming institutional bureaucratic processes. There was a demand for more time given by doctors for the consultation process but the time required for other institutional bureaucratic processes was the major drawback of services from government hospitals. The time dimension (promptness in initiating the treatment and total time consumed for the entire treatment process) in care seeking journey became more important as the distance from their village increased. Expectations around the time required for service delivery were different in for OPD setting and for hospitalization care. The nature of the illness, the seriousness of illnesses and the need for advanced interventions or surgical interventions also affected people's expectations around timely services.

During hospitalization care also time dimension plays out in a significant way, long hospitalization process with free services in government hospitals means disturbed families in

the village with some able attendants with the patient in the hospital whereas private hospital hospitalization has a meter of charges running for the duration of hospitalization.

The old adage, time is money, came very evident in assessment and reflection on their care-seeking journey. Most of the care seeking for the villagers in Panshevadi was from Kandhar town it was then followed by Nanded town. Time became an important factor even for this rural, primarily agricultural community as and when health care seeking was from a distant town.

For routine and minor illnesses, if they were to go and seek care from Kandhar then they go to Kandhar after finishing their essential task at home, take a consultation from a doctor, buying medicine and if there is any other important work in town, finish it and return. Distance of around 15 Km takes 30 minutes of travel however less frequent trips of Auto/Jeep running between Panshevadi and Kandhar takes additional 45-60 minutes wait. Thus effective travel for one-way travel is on average one to one and half hours. This privately running transport service is usually available between 7 am to 7.30 pm. These transportation services and their timing govern their health-seeking behaviour to a significant extent. *When asked specifically about the* ***good infrastructure and amenities available along with the clean environment at private hospitals and its influence in preferring the private hospital they (Sulekha's family) clearly told that that was not their primary concern. They told me that they are not going to stay there for long, it was just a temporary stay and hospitals cannot be as clean as homes. They reaffirmed that they prefer private hospitals as it offers them quick care, along with some visible efforts put in by the doctor and relief from suffering. Quick relief from the symptoms and cure of the disease was seen as important specifically when they go to seek treatment outside their village as they want to and have to return back to their homes as early as possible. (If it is daytime some flexibility is available but only till the time when transportation services in the form of buses or auto rickshaws are available. At night times, for emergency services, if treatment is given quickly and relief from the symptom is offered quickly then they can return back by the same private vehicle hired for transporting the patient to the hospital.)***

If they have to take treatment from Nanded then an additional effective travel time of 2- 2.5 hours (including waiting time for bus) is needed for one-way travel to Nanded 55 km from Kandhar. This makes the health care seeking journey even more difficult, if one has to take a

patient requiring some assistance like children, elderly, disabled or seriously ill patients then this journey becomes more tedious. This long travel of changing public transportation vehicles to reach the government hospital OPD within the prescribed time, going through long waiting lines at hospitals and returning home the same day is very challenging with a high probability of risk of finding oneself stuck at Nanded or Kandhar without any public transport available and one is forced to hire an expensive private vehicle to go home. *Vithoba More while discussing the care-seeking journey of his child and wife told, Government medical college and district hospital at Nanded have not resorted for the reasons of unsuitable timings of the district hospital along with heavy rush and long queues at the district hospital. It was very inconvenient for him to be a clerk in the government office to manage the office timings and to go to the district hospital within time, and return back by completing the treatment, given the heavy rush and department-to-department or door-to-door running involved in the district hospital. He expressed his opinion that the possibility of getting the best and correct diagnosis is at government hospitals as there are no private economic interests or profit motives. He also said that he would have given first preference for going to government hospitals but long queues and heavy rush are some of the big hurdles taking a lot of time there.*

The sensitivity and preference of community members for timely services are known to healthcare providers also. Most private GPs know this and accordingly give prompt services to attract new patients and retain existing patients. However, sometimes the vulnerability of people around the timing of service delivery is used by healthcare providers to corner patients to accept some services. *After reaching the Padam hospital Sulekha was admitted there at 4 am. Her relatives, parents and father-in-law, requested a doctor for trying out normal delivery. The doctor also promised them of doing normal delivery after examining the patient. Throughout the day she was in labour in the hospital and was constantly examined and monitored. Toward the end of the day, the parents and father-in-law of the Sulekha requested asked the doctor whether it was possible to do normal delivery, if normal delivery is not possible and there is a chance of doing a caesarean section then they would like to take the patient to the district hospital at Nanded for further treatment. They also requested the doctor to inform the doctor about his decision by 10 pm, so that they can arrange for Sulekha and their transport to the Nanded district hospital. It would have been difficult to arrange a vehicle after 10 pm at the night. The doctor examined the patient again and promised them of doing normal delivery. After midnight*

at around 12.30 to 1.00 am doctor told them that she requires an operation and the choice was given to either get operated on there in the hospital or to shift the patient wherever they like. At this hour of the night there was not any option available in this new town for them but to get operated there, as no private vehicles were available in the market to shift the patient. The doctor told me that normal delivery is not possible and CS is needed without even explaining the reasons for doing the same. They agreed to the operation and requested a doctor about the safety of the mother and the baby. They felt cheated.

The vulnerability of rural people over the timing of health services and access to transportation services is exploited by often government hospitals by delaying service delivery. In-ordinate delays in the care provided forces patient to look for alternatives in private hospitals and reduce the work of government hospital doctors. *Paraplegic and bedridden developed an ulcer on his sacral region. The ulcer increased in size very quickly to affect his buttock. It had an infection and there was fowl smelling purulent discharge from the ulcer. He showed it to the doctors at PHC. MO a PHC advised him to the district hospital.* ***He along with his wife took the challenge of travelling to Nanded and reached SGSMC and the district hospital and got an OPD paper. He consulted a doctor in OPD. Here he was investigated for X-ray and USG abdomen. He spent almost his whole day in the hospital getting these tests done. (These tests were of questionable use for treating a bed sore on the buttocks of a paraplegic patient. The test could have been done after dressing too or both could have been done easily by admitting the patient.) Late in the evening, he was given some tablets, syrup for relieving constipation and come cream for applying on the ulcer. When he inquired about the possibility and need for a dressing of the affected area they told him to wash his wound and apply the cream at home. He waited there requesting them to treat his painful bed sores. He was told to leave the hospital as the night set in.*** *He then had to request and beg the hospital staff for allowing him to stay as it was late and there was no possibility for him to get a vehicle so late in the night. He could not have afforded to spend on privately rented vehicles. He was allowed to stay but he was again told to leave the hospital premises early morning before dawn.*

He then decided to go to an ayurvedic hospital. Unfortunately, that day was a holiday. He went to the ayurvedic hospital emergency department. Here ***he was told that he would need dressing, some injections and medicines which can't be given from an ayurvedic hospital (though this***

ayurvedic medical college has fully functional OT and does major surgeries). He was advised and referred back to the SGSMC and district hospital. *Now he had nowhere to go. He spent his whole day on the street along with his wife. By now his wound had worsened with one more opening on the buttock with fowl-smelling purulent discharge. With none of the government hospitals showing any sensitivity to his suffering and after spending a day on the street he was left with no option but to resort to a private hospital. With the financial crunch, he opted for one trust hospital which ran on a no profit no loss basis, Tayar hospital. Here he was admitted for one month, where he was diagnosed as having a sinus. He then was given regular dressing and some medicines and antibiotics. He had spent almost 20-30 thousand on hospital stay and treatment there in Tayar hospital and there were separate additional costs for medicines and food for himself and his family members attending him. During this stay of one and half month's stay at the hospital, his whole family again got disturbed and was in disarray. He had to sell off his land to meet the expenses of the treatment cost.* Timely treatment and dressing of his bed sores by a PHC doctor or any of the doctors attending him from two medical colleges would have made a lot of difference in his life and it could have avoided the distress sale of his agricultural land.

Keshram while reflecting on his experience told t***imely services and interventions by the health workers specifically by doctors were very important. (Patients are often scolded by a doctor for not seeking care in time for illness and allowing the illness to become serious). If one does not receive timely interventions specifically in urgent and critical or painful situations the services are considered insensitive. If one does not get timely services means the patients have to suffer more, and the disease condition might get aggravated and can lead to complications***. *He also conveyed that it does not mean that every patient needs doctors with them around the clock but doctors should be available whenever the situation needs them to be there or till the patient is stable. I****f services are not provided on time then the option of getting services from other sources, private, have to be and are explored as patients and attendants cannot wait long when one is not even sure about the relief from the suffering and treatment even after the wait.*** *His experience of seeking care and the time needed for it in a government hospital has already been discussed in the previous chapter. Bringing attention to the basic level of* ***PHC in the village he told that of the two doctors only one doctor is available and doing duty at PHC. The doctor who is doing duty comes at 10 am in the morning and leaves by afternoon. So he (Keshram)***

told that even if doctors and other staff do their duty as per given timelines then many of the problems can be averted.

For serious illnesses and advanced treatment intervention, community members understood the importance of being patient and giving the required time for treatment. Doctor when satisfactorily explained the reason for the long time needed for treatment then they were accommodative of these delays. *Bishan and his family while reflecting on their experience of taking treatment for one month from a government hospital told that the drawback of the government hospital as they felt was that it was more time-consuming. However, they believed the government hospitals provided thorough check-ups and complete and comprehensive care. He further told that he would suggest the government hospital for others to seek care for their illness. When asked about the long duration of time they had to spend to get that care he replied that if the condition of the patient was such and needed time, as satisfactorily explained to them by the doctors, then there is no point in rushing things unnecessarily. They did not mind waiting because they developed confidence in the doctor's effort, as seen by her near-complete symptomatic relief from the condition. The wait ended with satisfactory results in terms of a complete cure for the condition.*

5.8 Experience with Referral services

The over-interaction with the community gave the impression that referrals of the patient to other and higher levels of care centres served as a gentle/subtle way of avoiding work and health care to the patient; refusing care; punishing patient- especially those who demand accountability and answerability from the doctor; avoiding responsibility; as a mean for earning commission through cut practice.

The availability of a functional referral system is useful in optimizing health resources and helps patients in getting the required health care as per their needs. A good referral system also helps patients in navigating the complex health system and helps in making decisions during the care-seeking journey. The Referral system, its nature and its organization are part of the institutional mechanism and also has been discussed in an earlier chapter on institutional processes.

The advice and suggestion for referral are given by a doctor therefore some aspects of referral service are discussed in this chapter. The advice of referral from one level of the institution to

other or from general services to specialist services is given by a doctor. Nature of referral service for its timing, reason, referred institution/provider ability to address the problem, preparation and treatment given before referral, treatment and care provided during transportation for referral, provision of adequately equipped transportation medium, necessary medical records while referring, intimation to the referred institution, follow up of referred patient, functional reverse linkages between two referring institutions etc. are part of institutional arrangement. However, many of these components involve interface with the doctor is the responsibility of the care provider or doctor in charge of institution referring.

The unavailability of a transport vehicle with referring institution was acknowledged and accepted as given. There was some concern about the unavailability of economical/ free patient transport for a referral. However other concerns around referral services were highlighted more.

Referral services are for helping a patient in the care process to get expert opinion and service from a higher level of institution (or of particular speciality) that is not available at a lower level of the institution. The referral services are for completing the requirement of the care process by taking the help of relevant opinions and services that are not available.

However, many times referrals are done for opposite reasons. *Purushottam Waghmare while commenting on services at PHC told that if the doctor is not present in PHC, the nurse available there mostly advises the patient to go to kandhar or Nanded. At RH kandhar, there is a very slow and delayed treatment service. If a patient demands services and timely attention, then patients are told that they can't manage this kind of illness at this level and patient will have to be taken to Nanded. If you need services to be provided in a better manner go to a private hospital. This is done to get rid of a patient who demands care and treatment or a patient who would need the time and attention of a doctor if admitted there. Sometimes patients, especially vocal and demanding, are referred out to teach a lesson to the patient by making them spend time money and energy getting treatment from Nanded. The doctors have nothing to lose, all he has to do is write on paper. A doctor can make use of any reason to refer you out and one cannot contest that. Referring out a patient makes his job simpler. If it is an unnecessary referral, then the patient has to go through that process. He also added that at RH sufficient machinery required for doing tests to treat patients are not available so patients are referred out.*

Patients are referred out so commonly for simple reasons that the community have stopped going to PHC and RH. Hardly anyone from any Sub-Centre or village nearby comes to PHC OPD treatment given its unreliable OPD services and very common referrals. RH kandhar was rather very infamous for referring out most of the cases that are taken there, especially during an emergency. RH kandhar is often used only for emergency services and community experience was of referral out to Nanded. Referral for delivery services is so common that many community members told that, mothers referred out from PHC and RH to Nanded get delivered (give birth to a child) in transport vehicles like Auto-rickshaw or Jeep on the way to Nanded. Therefore, the practice of unnecessary referrals from qualified doctors and health care institutions for simple and common health conditions was seen as marking poor services.

Patients were referred out from PHC to Kandhar for simple fevers, simple wounds and sometimes even for removal of sutures from a wound or surgical scars. *Ranpat told that he had an injury, and in an emergency, he had to go to Kandhar, he got his wound sutured by a GP in Kandhar, and after a few days when he requested PHC medical officer to remove the suture, he was referred out*. Most of the patients while narrating their experience of advice of referral from PHC consisted only of casual comments that, this condition can't be managed here and go to Kandhar. There is no advice given on where to go in Kandhar, whether to visit RH or any particular provider that he thinks is appropriate for the condition under consideration. Neither there is a referral slip given nor do institutions, where patients are referred, ask for any referral paper. ***PHC MO doesn't mention any name or hospital or RH at Kandhar they just advise them to go to Kandhar.*** *Recollecting the experience of taking mother-in-law to the PHC the daughter in law told that the doctor at* ***PHC did not give any help for treatment, nor did they help in removing her sutures from the surgical wound(the operation was done at DH Nanded), he simply told them to go to the place where she was operated*** *(Mayabai). A similar experience was told by another* ***villager who had to go to Kandhar for removing sutures from a wound on the leg as a doctor at PHC had refused to remove the sutures and had told them to go to a place where sutures were put in***. *It shows the dismal condition of referral services and near non-existent reverse referral linkages.* In the previous section, the case of Shambhu discussed shows how a simple case of bedsore was not treated within time at PHC and referred out leading him to a complicated infected sinus requiring hospitalization and pushing his family into impoverishment**.**

The probability of a callous attitude in referring out patients is more if the patient is poor and powerless. Referrals are advised in a manner that they are no different from any layperson advising you to go to the hospital to take treatment. There are no records given, no specificity in advice nor is there any care ensured during the intervening period required to reach referred institution. *Ganraj's son had a snake bite and was taken in an emergency to RH kandhar. Here he was given a few injections. He developed a reaction to the injections. Doctors from RH advised them to go to Nanded. They got out of the hospital and waited on the street to find some vehicle to go take the patient who was in pain with his oedematous swollen limb due to a snake bite and rash all over his body. After a couple of hours, they managed an auto-rickshaw to transport the patient to Nanded. Kandhar RH did not provide them with an ambulance or even did not suggest an ambulance. There was no IV cannula inserted when the patient was advised to go to Nanded. No referral paper or advice was given as to where to go in Nanded. On the advice of an auto driver, they went to and were admitted to the government hospital at Nanded, where he was treated for 15 days. He was restored to health.* Thus even life-threatening emergencies sometimes are referred out in a callous manner. This particular case gave the impression that the referral was given in this manner because in case of some serious complication or death of the patient nothing could be traced to a lower level of institution/provider and no responsibility could be fixed. Referrals done by these lower levels of institutions sometimes make it difficult to understand the reason for these referrals. Referrals are advised to shirk away the responsibility of treating a patient. There was a trend of referring away patients as early as possible from PHC and RH.

Experience of referral services in **the private sector** brought a different set of relevant issues. Unnecessary referrals or delayed referrals and motivated referrals for cut practice were reported from their experience with referral advice. It was observed that sometimes referral advice or its timing is such that the patient decides to continue treatment. *Dr Bawadekar told them that Mayabai will need an operation for removing her gallbladder. The total cost of operation as told to them was around 18-20,000 Rs. He advised them that they should get the operation done in the coming 15 days.* ***He further told them that if they don't want an operation from him then they might have to go to Hyderabad or Bombay for further treatment.*** *He prescribed her some medicines for the duration of a week and told them to come prepared for the operation.* **There is UG PG medical college in the town, and there is the availability of a significant number of**

surgeons and a few Gastrointestinal super specialists and surgeons' private hospitals too in the Nanded town therefore this advice of Hyderabad or Bombay raises doubt. It was almost panicking for the patient to take treatment from him.

In the case of child birthing, pregnant women are given a choice of caesarean section or referral out to the higher level of institutions at a very odd hour, late in the night so that patient is forced to take treatment from the same doctor. *Nayan requested the doctor to inform the doctor about his decision by 10 pm so that they can arrange for Sulekha and their transport to the Nanded district hospital. It would have been difficult to arrange a vehicle after 10 pm at the night. The doctor examined the patient again and promised them of doing normal delivery.* ***After midnight at around 12.30 to 1.00 am doctor told them that she requires an operation and the choice was given to either get operated on there in the hospital or to shift the patient wherever they like. At this hour of the night there was no option available especially for them in this new town but to get operated there, as no private vehicles were available in the market to shift the patient.***

Delayed referrals and dumb referrals also affect patients' well-being and health outcome. Dumb referrals are those where it is not even ascertained if the services /facility for which the patient is referred is available and functional at the referred institution. Delayed referral can happen due to delays in diagnosing the problem and sometimes for extracting some money through admission and some diagnostic testing (Diagnostic tests done without the possibility of offering treatment waste the patient's precious time and money). *Shambhu was then admitted to the Aksha Hospital under Dr Pagare. This hospital is a medium-sized (bed strength of about 30) multi-speciality hospital run by a group of doctors. Some of the doctors including Dr Pagare are full-time medical officers at district Hospital Nanded. Dr Pagare is M.S. in orthopaedics/general surgery. Shambhu was admitted here for 3 days. After an initial examination, he was told that he might need an operation on the cervical spine. Then he underwent many blood and radiological investigations like an X-ray neck and an MRI (4000 Rs) of the cervical spine. After the investigations, they told him that they will operate on the cervical spine and kept him admitted for 2 days. Later he was told that the operation was very expensive and was referred to the district hospital in the same city which is attached to the government UG and PG medical college. He was admitted to the medical college district hospital for 3-4 days where he was*

investigated for a CT scan. The same doctors who had checked him in Aksha hospital were the treating doctors here in the government hospital too. Doctors told him that they can't operate on him. He was given a cervical collar belt here. Then he was referred to K.E.M. hospital in Mumbai. He was taken to Mumbai by train. In K.E.M. hospital he was seen first in the emergency department and was kept waiting for 3-4 hours, during which he was lying down in the corridor. Then he was admitted to the ward where he was kept for 3 days. He was discharged from the K.E.M. hospital with few medicines for a week and a prescription for a waterbed with the advice of frequent shaking off water in a waterbed. He then was carried in a train in an unreserved compartment lying in between the seats to Nanded and from here in a privately rented vehicle to his village, Panshevadi.

After knowing about the nature of the injury to the spinal cord he is puzzled whether using a neck collar belt from the beginning would have helped him in some way, which was given to him on day 7 of the injury. He said if doctors at the Sub-District hospital had told him about the seriousness and nature illness he would have visited the district hospital without any delay, and he would have taken care of his neck movements to avoid further injury and dislocation of vertebras during the intervening period and while getting transported in this entire referral ordeal. He was asking me whether he was not serious enough to get referred in a hospital ambulance to the district hospital. He is agitated with the fact if he was having an ailment that doctors at apex hospital in Mumbai couldn't operate then why was he promised and advised an operation at Aksha hospital, to begin with, and was kept waiting for 3 days and was sent out without operation. He is curious to know the capability and experience of doctors at Aksha hospital in doing an operation on patients with an ailment like his, quadriplegia with a fracture at C3, C4 and C5 vertebras. He is still wondering if he had gotten proper advice and prompt necessary treatment would his condition have been different. He is very hurt and lost hope in medical professionals with the fact that none of the doctors from the allopathic system of medicine both in private and government ranging from the Sub-District level to the apex hospital in the capital city gave him simple and crucial advice on exercise and massage. Nor was he advised about the precaution to be taken during travel for visiting and returning from hospitals.

Lack of advice for further care by referring patients to an appropriate institution means patients don't receive complete and appropriate care. In absence of a such referral, patients have to live

with the implications of that partial and incomplete treatment. *Teena Kore had facial paralysis. She was examined and admitted to the ayurvedic hospital at Nanded. Doctors told her that she will get better in 3-7 days. She got treatment involving facial massages with different herbs. Different herbs and leaves were cooked and made into a paste and it was applied on her face regularly. She was also given some medicines to eat. She did not improve much in seven days. Her admission period was extended and she was kept under treatment for 15 days.* ***There was a partial improvement in her condition. She was discharged with partial residual paralysis of the face. She has residual paralysis of muscles involved in the movement of her eyes and mouth; one eye appears smaller than the other.***

Doctors in the ayurvedic hospital did not give any significant advice for further course of action. She was taken to the home and she is living with partial facial paralysis. *After one year her husband came to know about a similar case taking treatment with Dr Gajendra Patil (physiotherapist) at Nanded. She was taken to Dr Patil. He advised her to apply talcum powder and do massages of the face. She did it for some time without much change in her condition. They, she and her husband, think that if they had shown it to some physician (physiotherapist) like Dr Gajendra Patil at that time immediately, her condition might have improved significantly.* If one analyses her whole treatment experience, then one might observe that despite visiting the government ayurvedic medical college within the time she did not get better from her condition, Bell's palsy. **After completing the in-door ayurvedic treatment for 15 days and despite the presence of residual paralysis, doctors in the ayurvedic hospital neither sought an opinion from the next-door government medical college offering allopathic treatment nor did they advise the patient to seek an opinion from the government medical college or physiotherapist or any other private physician (MD internal medicine).**

This shows there is no dialogue between different government institutions offering treatment and it has implications for patients' betterment. One wonders what would have been the outcome if she was given a seven-day treatment with steroids which are taken off by tapering off the doses. None of the doctors had advised them to visit a physiotherapist and if she had received the physiotherapy involving faradic current stimulation of different facial muscles along with infra-red-light therapy to reduce oedema in the internal ear region the outcome would have been different. So one can say that she did not receive the

complete treatment, and none of the doctors advised them about the nature of treatment she might need if it was not available to them. She might have resorted to the appropriate and complete treatment wherever it was available.

Community members recollected some experiences of good referral service which reflected the caring attitude of the doctor. *Nanak More*

recollected Dr Ghardive who was a medical officer some 20 years back and said that he used to take responsibility for the patient and treat them, if he could not manage the case then he used to refer the case to higher levels. He used to take efforts of calling and reporting at higher levels where the patient was referred about the condition of the given patient. This acted as great support for the people. The referred patients used to get admission without much effort based on earlier discussions with medical officer Dr Ghardive.

Asaya was grateful for the experience that when she was taken to CHC Mukhed, a doctor gave her initial treatment and when he realized that it was a poisonous snake bite referred her to medical college and district hospital. The doctor had called an ambulance for the sake of her transport quickly from CHC to district headquarters, Nanded. The doctor had told them that they will have to pay 800 Rs for an ambulance. She was given a proper referral paper which helped her get admission to a medical college hospital.

However, none of the community members had the experience of a well-equipped ambulance with an on-board doctor and emergency treatment facility, therefore, it was beyond their imagination to expect or comment on.

5.9 Summary

Table 5.1 Desirable and Un-Desirable Aspects of Experience and Expectation from Clinical Care	
Desirable aspects of experience and expectation from health services	Un-desirable aspects of experience and expectation from health services
<u>System structure of health services</u> • **in house availability of different specialist** • **Availability of different diagnostic modalities and experts makes it easier that in due course of time the co-**	

existing morbidities are treated and complication can be avoided and handled with efficiency if any arises during the course of treatment. • Comprehensiveness is not only limited to having different specialist opinion and integrating/ synchronizing/rationalizing the treatment from all specialist. Comprehensiveness of all health care related services to give a wholesome care experience so that patient's inter phase with institution becomes comfortable experience • ***Availability of non medical services include provision of linen, clean bed sheet, provision of support manpower, transport for referral and very important and crucial of these is the provision of food from the hospital***.	
<u>Institutional features - input</u> • ***Equipped to do blood tests and provide whatever treatment that was needed***	
<u>Institutional features - process</u> • Attendants expected that patient is admitted and is given frequent attention, care and treatment • Attention and sincere effort by the doctor • *Personalized treatment, attention and care* • Wholesome treatment should be according to nature of illness, and should make use of diverse expertise if needed in treatment process to restore health. Advice on role of other professional intervention, without feeling competition from them, to maximize health benefits to patient was considered as better way of managing illness • **Treatment is provided with some manuski (human ature) and with responsibility and accountability** • ***Private doctors give care quickly*** • ***Personalized care.*** *Doctors and other hospital staff was talking to him,*	• ***Same medicines and tablets are given for the different illness.*** • This raised their suspicion on doctor's ability as well as institutions capacity to give treatment to diverse health needs of the community. • Insincerity, delay or irregularity in assessment of patient and required intervention becomes a grave concern • Lack of attention, sincerity or partial attention with tubular vision of the disease condition and neglect/disregard of overall health of the patient was also a matter of concern • Inconveniences that they had to go through or the unfriendly behaviour • In private everything is required to be purchased from outside. T**he materials like cotton, gauze piece, IV sets, gloves, spirit swabs, syringes** etc. also have to be bought

spending some time with him, helping him in doing his exercises • ***He felt that he was cared for, somebody is investing time, energy and skill to get him better*** • The genuine effort and sincerity of care provider • Diagnosis and treatment of multiple morbidities in comprehensive manner to restore health without having to search for different specialist • Services are preferred quickly • Institutions having less time consuming institutional bureaucratic processes. • More time given by doctor for consultation • Promptness in initiating the treatment and shorter total time consumed for entire treatment process • *Regular round for checkup were done by the doctors and* ***they spoke politely***	from the market in the private hospital • Institutional bureaucratic processes was major drawback • Long waiting lines at hospitals • *unsuitable timings of the district hospital* • *heavy rush and long queues* • *Heavy rush and department to department or door to door running involved* • *Long queues and heavy rush are some of the big hurdles taking lot of time there.* • In-ordinate delays
<u>Attributes and features of provider</u> • ***It is very important that doctor talks to them satisfactorily, and the patient gets better from the ailment*** • *Talks in satisfactory and humane manner.* • ***These actions in the form of various activities aimed at treating the baby gave them some confidence. They felt hopeful and confident as something was being done by the person, doctor, who knows about the illness and the treatment. He gave them a feeling of confidence; he displayed confidence in his behaviour*** • *Providing care by putting in their physical and mental energy.* • ***Doctor should talk satisfactorily and cure from ailment****.'* • *Satisfactorily explained* • Earnest advice, counselling and information given without any financial motives with patient's best interest in mind (as felt by patient)	• *Rude answers are more, and after that they feel insulted and then avoid talking to these staff members,* • *Tendency of the doctors to prescribe with many medicines raises doubts in their mind about the doctor and about the usefulness of the medicines prescribed.* • If they find flaws, inconstancies, irrationality or ulterior motive there then it acts as ground to discontinue the treatment • ***Government. doctors don't start the care and treatment soon and when started they don't even give it in satisfying manner with caring attitude.*** • ***Patient is neglected quite often in the government. institutions*** • ***Doctors don't want to take responsibility so all the time they want to send the patient away at***

• Adequate counselling of patient on accepting nature of illness, how to deal with or live with chronic disease is very important • Doctors sincerity, gentleness, confidence, earnestness, skills, efforts, promptness, caring attitude, • Moral character and conduct, professional integrity, trustworthiness, truthfulness and credibility • *Proper advice and prompt necessary treatment* • ***Hospital staff behaves in a humane manner with the patients.*** • ***Human nature and skills to interact with patients and the attendants***. • caring, sensitive, gentle, polite and humane behaviour • Give some confidence to patient and relatives, provide some assurance of cure, care. Assurance of at least of putting in sincere efforts to try and heal patient. • ***Assured of completely curing the baby and putting in all his efforts*** • *Doctor attends them without improper delay. He speaks satisfactorily, explains them about condition and, asks for medicines from outside if needed and treats their patient or gives necessary advice in case of referral.* • *He recognizes us, talks to us respectfully, enquires about us* • A nice person beyond his professional capacity • as nice person having human nature • relieving the suffering of the patient and giving proper advice in a satisfactory manner	***higher level out of their jurisdiction or at-least out of their institution.*** • Reluctance to give assurance and confidence of better outcomes • ***Concerns and doubts then are not answered explained properly.*** • ***rude answers are more, and after that they feel insulted*** • ***Doctors were in hurry to get rid of the patients as quickly as possible***. • ***Patients being shouted at*** • ***Concerns and doubts are not answered or explained properly.*** • ***Rude answers, they feel insulted*** • ***Rapid deterioration of manuski among the doctors.*** • Rude and insensitive behaviour of doctors • Feeling of being treated subhuman is insulting feeling.
<u>Medical/ clinical care components</u> • Doctor would listen to their problem, enquire about the problem and will do clinical examination • Discuss with them prognosis of the condition and then give some options of treatment and treat the patient	• ***None of the doctor in government or private hospital explained them the nature of the disease the prognosis, the nature of investigation and the treatment needed, the duration of the treatment needed*** • ***None of them gave any diagnosis,***

• relieving suffering. • Treating doctors should have given him choice and help in making an informed decision after due explanation about the disease, its prognosis, possible treatment alternatives available, with their merits and demerits along with success rates or failure rates of these modalities. • Should have told him about the success rate or prognosis of the disease with the treatment that was being offered by them. • ***Examines them properly, writes the prescriptions and explain them about where to bring the medicines from, the probable costs, and sometime the purpose of the medicines used. They even administer these medicines without any delay*** • *Doctors were serious about attending to his ailment and doing something* • *Thorough physical examination was done* • ***Prompt and frequent attention to the patient*** • F**requent attention and visible efforts by a trained doctor** • Reassurance is usually what is expected during hospitalization from doctor by the patient and attendants • ***Examined the baby thoroughly, he himself wiped the baby with cloth soaked in water. He took blood sample from the baby and gave it for sending it to lab. Then baby was put in IV cannula and given some injections*** • *Regular and timely attention* • Timely change in line of treatment if needed • Treatment was expected to be dynamic, and appropriate to changing nature of condition of disease. • Preferred regular expert attention, examination and monitoring. • Expected gentleness and dignity during these clinical examinations and medical interventions.	***nor did they explained about the prognosis of the condition.*** • Don't answer the queries of patient around the nature of illness and prognosis of the disease • *None of the doctor even touched him.* • *His 6 hours wait was for may be six minute consultation, where doctor did not even touch him. Thus there was complete lack of warmth and caring and sincere attitude in the consultation that was being provided.* • The advice given is not only inadequate at times is wrong and motivated. • Wrong and motivated diagnosis of disease condition and its treatment • Treatment inadequate even in terms of giving professional opinion or differential diagnosis of condition that they are treating. • Sometimes there was wrong diagnosis and advice given raising a suspicion about it financially motivated. • ***Doctors don't examine properly,*** • ***they neither explain them anything about the medicines, the purpose of the medicine, estimated cost, where to bring it from nor do they administer the bought medicine to the patient immediately*** • ***Same medicines and tablets are given for the different illness.*** • ***Very cursory and superficial examination that he did of her wound*** • ***She doubted the doctor's opinion about the type of snake that had bitten her*** • ***So overall experience of lack of sincerity in the examination, doubtful judgment of the type of snake and the financially motivated advice of expensive set of un-necessary operations contradicted***

• Explanation of disease condition and advice given by the doctor for treatment and care also mattered to them • Explaining about nature of illness to the patient, explaining the line of management and nature of what the treatment is and how it might benefit in relieving suffering was enriching and empowering experience for the patient. This practice made them feel being treated with some respect and dignity. This practice enabled, empowered and motivated them to take active part in the process healing their own selves • ***Thorough check up and complete and comprehensive care***. • ***Rational care*** • ***Getting correct diagnosis of the condition and rational treatment*** • ***If we get relieved from the symptoms then we call that treatment as good treatment.*** • Recovered from the disease and are free from suffering then they considered treatment was good • ***Free from those symptoms and suffering now*** • **Cure with some dignity and respect** • ***Complete symptomatic relief*** • ***Complete cure from the condition.*** • In the absence of complete cure, nature and degree of relief offered • *Appropriate discharge and closure of case* • Adequate time given by doctor (to understand patient's problem listening to what patient has to say carefully and asking some questions to understand the nature of problem) , explaining them nature of treatment given, how medicines are to be taken, the precautions to be taken during treatment, possible side effects, disease aggravating or relieving factors etc.) was reported as important reason for going to private provider.	***and crashed their belief and expectation from this famous doctor.*** • Unnecessary investigations, prescription of medicines, surgical procedures to earn more money by health care professionals • ***Private hospital are quick to act in doing any procedure and operation without trying out medical and conservative line of treatment as that big procedure or operation gives them more money***. • ***Unethical practice by doctors in terms of un-necessary operations for extracting money.*** • ***Prescribe lots of medicines and many of them are usually un-necessary.*** • ***irrational treatment*** • **Unnecessary diagnostic tests, medicine prescriptions, admissions, surgical procedure** • *Disappointed as she did not get any relief from symptoms.* • Non relief or partial relief from symptoms was considered as wastage of money • ***None of them even the orthopaedic and other specialists was gracious enough to accept their limitations in diagnosing the case and referring them to appropriate specialist*** • ***doctor did not give them proper advise and treatment.*** • ***They feel that if the case was beyond their management, the doctor should have referred it to appropriate centre. Despite spending so much money patient lost his life*** • Feeling of being cheated by doctor in care process • Unnecessary and excessive prescription of medicines • Doctor cornered them in to situation of helplessness and exploited their vulnerability to earn more money

• Time given for satisfactory information and counselling was considered as valuable as medicines • ***Gave proper time for inquiring and examining the patient.*** • *Possibility of getting best and correct diagnosis is at government hospitals* • When satisfactorily explained the reason for long time needed for treatment then they were accommodative of the long duration treatment • ***Appropriate time to examine the patient and take proper history. Doctor should understand the patient's concerns*** • ***Patients are provided with information about the nature of illness and possible treatment option.*** • ***Doctor and other hospital staff should behave in humane and polite manner*** • Convey limitations of personal or professional capacity including inadequacies of scientific knowledge in dealing with the health condition that is being treated, so that patients and family members (especially in case child patients) are able to cope with it in better manner • *Doctors should be available whenever situation needs him to be there or till patient is stable* • Nature of referral service for it timing, reason, referred institution's/provider's ability to address the problem, • Preparation and treatment given before referral, • Treatment and care provided during transportation for referral, • Provision of adequately equipped transportation medium, • Necessary medical records while referring, intimation to referred institution, • Follow up of referred patient, • functional reverse linkages between two referring institutions	• The consent given for surgery was for a particular doctor and this was not honoured. • Malpractices are perceived as very serious issues • A doctor intentionally doing harm to patient or contributing to deterioration of his health is serious breach of professional integrity. • *Initially promising and later refusing an operation that they don't have capacity to do.* • ***No improvement in his condition*** • ***the doctor had replied them that he was specialist of brain and he was treating his head injury, so he was not answerable to paralysis in limbs.*** • No advice by the doctor for physiotherapist and speech therapist, not even the suggestion for doing massage and movement of limbs had resulted in contractures in his limbs. • *Unethical practice to earn more money.* • *Incompetent doctors* • *Referrals for- avoiding work and health care to patient; refusing care; punishing patient- especially those who demand accountability and answerability from doctor; avoiding responsibility; as a mean for earning commission through cut practice* • Practice of unnecessary referrals from qualified doctors and health care institutions for simple and common health condition was seen as mark poor services. • No advice given on where to go in Kandhar, neither there is referral slip given nor do institutions where patients are referred to ask for any referral paper • Referrals are advised in manner that they are no different from any lay person advising you to go to hospital to take treatment. There are no

	records given, no specificity in advice nor is there any care ensured during the intervening period required to reach at referred institution • Should not have been advised discharge before complete recovery • Unnecessary referral or delayed referrals and motivated referral for cut practice were reported • Dumb referrals are those where it is not even ascertained if the services /facility for which patient is referred is available and functional at referred institution. Delayed referral • Lack of advice for further care by referring patient to appropriate institution • none of the community members had experience of well-equipped ambulance with on board doctor and emergency treatment facility therefore it was beyond their imagination to expect or comment on
• *self-respect, dignity*	• the price that one has to pay for it. • Cut practice and financial kickbacks
	• The nature of documentation (of illness, examination findings, test results, differential diagnosis made and treatment given) done by doctor and given to the patient also gives some indication of quality of that inter phase with doctor. • ***None of the consultation paper had mentioned anything about differential or probable or definitive diagnosis they had thought about while prescribing the medicines. Medical records handed over to the patient had very little information to decipher anything about the past medical condition of the patient. This was observed in most of the***

	people I visited and have had look in to their medical records. • The communication by doctor with patient on the test results did not match with available test results.
	• Biased way of revealing and hiding diagnostic finding from patient has implications for wellbeing of the patient. • *USG renal calculi*- ***She was not even given simple advice of increasing water intake. On the other hand, she was advised hysterectomy.*** **Even, while advising a major surgery like hysterectomy the indication and reasons for doing operation was not explained to patient.**
• ***Thus the confident behaviour backed up by the infrastructural facilities to investigate and treat the patient along with caring attitude and assurance about curing the baby was very important***	

Chapter 6 Quality Considerations from Therapeutic, Nursing and Support Services

6.1 Perception of Quality relevant to Therapeutic Para-clinical and Nursing Services

6.1.1 Therapeutic Services

Services of health care providers, other than doctors, such as physiotherapists, occupational therapists, audio and speech therapists and counsellors are professional care services of immense value in preserving, maintaining and restoring the health of individuals. These services can be offered independently, according to the needs of the patient or in conjunction with services of a doctor (modern medicine/ or AYUSH). The services provided by these professionals, in their own right, are clinical services with preventive, curative and rehabilitative aspects built into them. These services have been discussed in this chapter under the broad heading of para-clinical services. The word is chosen for the lack of a better alternative and to distinguish them from the services provided by a doctor. This distinction was considered important to recognize and give these therapeutic services the due space and highlight the invisibalisation and neglect that the area receives in the care-seeking journey. Some respondents who had used these services had very positive experience with them, where they felt cared for; therefore, it was important to discuss these services separately.

In the small village from which this small sample was selected for, several cases requiring these therapeutic services were found. Illnesses like hemiplegia, paraplegia, spondylitis, facial paralysis, injuries, joint pains (arthritis), accidents, pneumonia, diabetes, stress etc. were reported from the selected sample. Cases of mental health problems, developmental delays and disorders among children were avoided by the researcher because of possible emotional breakdown among respondents even though patients with all these illnesses were also encountered during the study period in the village. In ideal medical practice, all these therapeutic professionals have established roles in the care process of different illnesses.

The community was often using services of specialist and super specialty doctors from diverse private hospitals and the medical college hospital in Nanded. Community members were aware of super-specialty services and were keen on using them depending on the requirements of their illness. This awareness though, was in the form of knowing their area of specialization, like a

heart specialist, kidney specialist, brain surgeon, hearth surgeon etc. However, most of them were unaware of the exact educational qualifications of the specialist doctor. There were people in the village who had undergone an angioplasty, bypass and brain surgeries etc. In a community with a high frequency of use of such advanced medical intervention and specialty services, it was important to note that there is a comparative lack of awareness of even the existence of professions like physiotherapy, occupational therapy, audio-speech therapy and psychological therapy (counselling).

Very few community members were aware of such professionals. They just knew of physiotherapists as doctors of exercise. Those made aware of para-clinical services, complained that their treating specialist doctors did not inform them of the availability and role played by such therapeutic professionals. Few who were told about such professionals were informed of them too late in their care-seeking journeys. *After unsuccessfully trying out treatment at a private hospital, the medical college hospital of Nanded and the one in Mumbai, with little improvement, Shambhu spent six months at home, losing all hope of further treatment and recovery. After six-months however, Shambhu got admitted in the Ayurvedic medical college at Nanded. Here the doctors and other hospital staff spoke to him, spent time with him, helped him in doing his exercises. A professional masseur was available (though not hospital staff, and had to be paid for from one's own pocket, they provided services to patients with different kinds of musculoskeletal disorders and paralysis). The massage sessions made Shambhu feel cared for. He felt someone was investing time, energy and skill for his recovery. He was told about the importance of massages and exercises and although he had already developed contractures in his palms, elbows and foot and there was wasting in his hand and lower limbs. Massages and herbal hot fomentation improved his condition, his contractures relaxed a bit and he had more power in both his limbs to the extent that he could stand with the support.* ***When he realized that his contracture had relaxed with the massage and exercise, he was also informed that they could have been avoided if he had consulted a physiotherapist and exercised the muscles and gotten massages right from the beginning. It was in that hospital that he was informed about physiotherapists and their role for the very first time****. He recalled his experience with hospitals at all levels viz. sub district hospital, multi-speciality private hospitals, district hospitals with UG and PG teaching and the apex hospital in the state capital of Mumbai also having UG, PG, super specialty and allied medical training facilities including physiotherapy. He wondered*

whether his state would have been better or could he have recovered much sooner and not developed contractures, had he been informed about the exercises and massages.

None of the respondent community members in their interviews or in the group discussion mentioned anything about having received these therapeutic services at the medical college and district hospital. Many respondents who had received care from the Ayurvedic medical college hospital mentioned that they had received massages and exercise therapy there. However, people were doubtful, as can be seen from Shambhu's experience whether the masseurs in the Ayurvedic medical college were trained therapists. If some of them were qualified physiotherapists, then the lack of recognition of this profession and its role needs to be mentioned. Lack of sufficient number of such trained professionals in the district could be one reason for them not being part of community memory and experience so far.

Young Ganesh's experience revealed that he was not given timely advice about the role of the physiotherapist when he was first admitted, for nearly 5-6 weeks at the neurosurgeon's hospital for his post-epileptic head injury. Ganesh suffered head injury due to a fall during an episode of epileptic seizure. He was admitted to the private hospital of a well-known neurosurgeon in Nanded. His relatives were not allowed to meet him while he was in the ICU except for a few minutes 2-3 times a day. After a few weeks of treatment and having spent a few lakh rupees, his family members started realizing that there would be no recovery as far his paralyzed limbs were concerned. When this was brought up with the doctor, he shouted at them saying he was treating his brain and was not responsible for the paralyzed limbs. Even after 5-6 weeks of stay, when there was no recovery from paralysis and the family had exhausted most of its financial resources too, the patient was discharged from the hospital at the request of the family members. It was at the time of the discharge that the doctor casually mentioned consulting a physiotherapist. At the time of this study, Ganesh was living with contractures in both his limbs and speech that had been affected. The family got to learn about the role of the speech therapist very late from someone known to them. They then consulted a speech therapist and physiotherapist later. There was some improvement in his condition but they wondered, whether Ganesh's condition may have been different, had they been advised of physiotherapy and speech therapy earlier.

Non-inclusion of therapeutic professionals in the patient's treatment process or delay in including them in the care process was observed not only in the profit-oriented private hospitals for fear of losing the patient but was also observed in patient experiences of care-seeking at government hospitals. *Teena Kore was admitted for facial palsy at the Ayurvedic medical college hospital, but the period of admission was extended and she was kept under treatment for 15 days.* ***There was partial improvement in her condition, when she was discharged she had partial residual paralysis of face. At the time of the study she still suffered from residual paralysis of muscles involved in the movement of the eyes and mouth; with one eye appearing smaller than the other. Doctors in the ayurvedic hospital had not given her any particular advice for future course of action. She was taken home and was living with partial facial paralysis since then. After ayear, her husband came know of a similar case obtaining treatment from Dr. Gajendra Patel, a physiotherapist at Nanded. She was taken to Dr. Gajendra Patel who advised her to apply talcum powder and massage the face. She did it for some time with little change in her condition. She and her husband, conjectured that had they consulted a physician (physiotherapist) like Dr. Gajendra Patel immediately after her medical condition set in, she might have improved significantly***. The analyses of her entire treatment experience, reveals that despite visiting the government ayurvedic medical college in time, she did not get full recovery from her condition- Bell's palsy. Timely physiotherapeutic interventions like faradic electric stimulation, infrared light therapy, exercises are known to help in the recovery from facial palsy.

During his care-seeking journey, Bhagirath for his neck pain, Pitamber for his spondylitis and limb weakness/paresis, Shambhu for his paraplegia have had very satisfying experiences of being cared for, had experienced some improvement in functionality and were relieved of pain with the massages and exercises (components of intervention of physiotherapist and occupational therapist) that they underwent at the Ayurvedic Medical College. Unfortunately, there were not many experiences of care-seeking with these therapeutic professionals to understand if and how they contribute to patient's wellbeing and patients' experiences about the care they received from them. This absence was an important finding.

6.1.2 Nursing care

Nursing care was another important professional service shaping people's experience during health care-seeking. The ANM and LHV at the level of SC and PHC were health care providers

for minor illnesses and for illnesses covered under different national health programs. GNM, BSc nursing professionals play important roles in hospitals performing a wide range of roles in addition to their main role of providing nursing care.

The ANM and LHV act as the first point of contact with the health service system for the rural community in India. With the rapid increase in number of doctors (of all systems of medicine) more doctors were now available at block town. Large villages also now have 2-3 GPs. Many GPs and sometime specialist doctors also provide OPD services on fixed days of the week or month in many villages. With this increased availability of doctors and increased better availability of public transport like auto rickshaw, jeep, bus etc. doctors are now replacing ANMS and LHVs in becoming the first point of contact of care for populations.

Nursing staff as care providers in the OPD setting:

ANMs and LHVs continue to perform the role of care providers to some extent for minor illnesses and to a great extent for MCH services like Family Planning, ANC and immunization. They serve as care providers with ANC services for pregnant mothers. Community members, especially mothers of young children and pregnant women shared their experience of seeking care from nursing professionals at the level of their village (PHC village where only an ANM resided and provided services round the clock). *Kavita Hiraman More had two daughters and was pregnant a third time when she was interviewed. She was in the seventh month of her pregnancy that had started during a period of lactational amenorrhea.* ***She found out about her pregnancy after she visited the ANM Gawade sister complaining of nausea and vomiting. After a urine test at the PHC, the ANM Gawade confirmed her pregnancy. The test was free of cost. Kavita was then registered at the ANC clinic, and the ANM informed her about the number of TT injections she needed to take in the fifth and seventh months. The ANM had called her to the PHC during the fifth and seventh months of her pregnancy where she had two doses of the TT injection. She also received a strip of 30 iron-folic acid tablets in the sixth month of her pregnancy. The LHV Patel sister had taken her blood sample and shared the test results- they were normal. During these visits to the PHC Kavita was also tested for her blood pressure and weight****. On inquiring further, she revealed that she had not been given any advice for her dietary intake or rest. Till the time of this interview,* ***she had three visits to the PHC; the first at the time of the detection of pregnancy, the second in the 5th month and the third during***

the seventh month. During her visit in the fifth month, she had been examined for her weight and blood pressure. During her visit in the seventh month, she was examined for her height, weight, blood pressure, per abdominal and blood examinations. She had been given an ANC card and all her examination details were entered in there. She had delivered her first two children at her natal home in Loha and planned to do the same for the third pregnancy as well. During each of these visits, the doctor was present at the PHC, but all pregnant women including Kavita were examined in a separate room by the ANM Gawade. There were about 5-6 pregnant mothers at the time of her ANC check-up. On asking whether she wanted an examination from the doctor, she said that most of her concerns were being addressed by the ANM who called her up for the examination and made her comfortable during the manual examination with very friendly and helpful manner. Hence, she said that she didnot feel any special need for a doctor or a lady doctor to perform her ANC examinations and consultations. She expressed satisfaction with the level and kind of services that were being provided for pregnant mothers at the PHC

Sister Gawade had been posted in Panshevadi village since a long time and she resided in the village as well. Therefore, she was available beyond her official work-hours, when the doctor was not available. She was easily accessible in the village, because of which she was consulted frequently for common and minor illnesses. In one of the discussions a group of community members were mentioning her. They *praised ANM Gawade for the respectful way in which she talked to them and treated them. During her home visits she gave them tablets and injections, and provided nebulization to their children whenever they needed it. The community members also said that they preferred visiting her over one more sister who was from their own village (she had been married into family in Panshevadi but their family resided in Kandhar). One of the women from the community, Krishna's mother said that when Gawade sister was on duty in adjacent villages, she made sure that she visited her early morning before 8 am, i.e. before she left for other villages to give injections as a part of the course prescribed by the paediatrician at Nanded. Krishna's mother also complained that she was not given injections and medicines on the grounds that she lacked blood in her body and was often referred to Kandhar*.

Roles and responsibilities of nurses in hospital setting are different as compared to job requirements of ANM and LHV in the field setting. Nurses perform wide range of tasks in

hospital setting. Experiences with some of these roles and responsibilities of patient during their care-seeking journey as relevant to understand their perceptions of quality are discussed here.

Nursing care during hospitalization:

The nurses were mentioned by people while sharing their experience of IPD care-seeking from government hospitals. Nurses despite being important professionals providing service in private hospitals also, did not figure in people's care-seeking experience in these institutions. The care-seeking experiences were all about doctors, infrastructure and services. There was complete absence of the mention of nurses or their role while sharing the experience of private hospitals. It might either be because the researcher did not specifically probe about nursing care obtained from the private hospital (most of the patient experiences were from small nursing homes and polyclinics their sizes ranging from 5 to 50 beds- no big corporate private hospitals) or that the nurses might have been very insignificant with no power in the decision-making and care provisioning to the patient. It is also pertinent to mention here that not all nurses were qualified in most small private hospitals in the district.

Narratives of care-seeking at government hospitals on the contrary, often mentioned their experience with nurses. Most respondents conveyed that they had bad experiences with nursing professionals while they were hospitalized. Nurses were often described as being rude to the patients, shouting at them, being careless, negligent and insensitive. The *government hospital staff neither explained anything about the medicines, the purpose of the medicine, estimated cost, the place from where medicines could be bought, failed to administer on time. If relatives or the attendants sought clarifications or expressed their concerns, they did not really get satisfactory responses.* ***In-fact the chances of getting rude answers were more. Once insulted family members avoided talking to the staff members- usually the nurses****.*

Besides, there were people had their own gendered stereotypes and patriarchal biases, that were revealed in some of the interviews, though some respondents also were reflexive during the discussion, while sharing their experience with nurses. On the whole, nurses at all levels of service delivery, from the PHC to the district hospital, were characterized as rude and unfriendly. Varied responses were given to question on the reasons underlying such behaviour of the nurses. *Radhabai described the nurses as very proud and arrogant. According to her, they thought no*

end of themselves because they had salaried government jobs that offered them a good remuneration so they viewed other women and patients as lowly beings. Radhabai's sons, daughters-in-law and other family members echoed her reasoning They said that doctors usually talked nicely, though occasionally doctors also shouted and behaved rudely with the patient and relatives. However, in comparison with nurses, doctors behaved nicely with the patients. The researcher probed about the differential work load, multiple tasks and duties to be performed and public interaction that different types of healthcare workers specifically doctors and nurses had to undertake. To begin with, Radhabai said that there was not much difference in work load. However, Sakharam, her husband said that the work-load was much more for nurses. According to him, the doctors usually just wrote commands and orders on paper but it was the nurse who did most of the actual work of providing treatment to the patient. The nurse was responsible for much of the allied work that was needed to run a hospital smoothly. The responsibilities of having to interact more with the public, and maintain discipline lay with the nurses; resulting in greater friction with the public. Their own heavy work-loads must be compounding their exhaustion and could be cause for their unpleasant behaviour. Gender stereotyping and expectations by the people could be affecting the nurses, and this rude behaviour could also be a defense mechanism used by nurses against these gendered expectations. Patients and relatives in the given power dynamics often may not be able to articulate their frustration with the doctors and might find it easier to divert it towards the nurses.

Asaya, who had been hospitalized at the government hospital was appreciative of the nursing professionals. *When asked about the rude, unfriendly behaviour by health workers specifically the nurses, she gave a balanced response. She said that the nurses had to ensure cleanliness and order in the ward. Many people, and patients from rural areas, did not follow the rules, pertaining to arrangements and cleanliness in the hospital so they the nurses would shout at those who broke the rules and dirtied the place.* ***It was the burdens of duty and responsibility that made them unfriendly and angry towards the attendants, visitors and patients who failed to follow the rules. They made people follow the rules about visiting hours, made them collect their garbage and put them in dust bins rather than littering the place. Their enforcement of rules could hurt the ego of some patients and their relatives. It was this rule enforcement component of their work that made them look like a demon in the eyes of the patients and the relatives. According to Asaya, the nurses did not shout at patients or people who were not at***

fault. She said that she got the best treatment at the government hospital. She got many injections, bottles of IV fluid one after another, at beginning two bottles of IV fluids were given simultaneously on both hands. According to her so many IV injections and fluids were the best possible treatment and they had saved her life. So to her mind, there was no attempt to be frugal on the part of government hospital while giving the necessary treatment to the patient. She said that the nurses were very quick and caring in giving these IV fluids day and night*. She also told that doctors and nurses at the sub-district hospital at Mukhed were also swift and handled the emergency satisfactorily, as one would expect.* ***They started the initial treatment and referred the patient to a higher institution, organized a proper ambulance from the hospital to save travel time, instead of resorting to the usual auto rickshaw****. She also said that as an in-patient at the hospital her experience with hospital doctor was good too. The doctor would come regularly to enquire about her condition, ask questions, spoke to her properly as well as examined her well when he advised treatment.* ***She also said that the nurses were caring and they used to change the IV fluid on their own even when patients were sleeping.***

When asked about the usual complaints against the nurses, she said that the nurses were under a lot of work pressure. Every patient and attendant demanded immediate, quick and personalized attention from the nurse whenever they felt the need. Small delays in visiting patients when they were called for could invite the wrath of patients, the friction that followed also led to the nurses shouting at the patient or attendants. The common reason for frustration against nurses was with regard to changing IV fluids bottles, once they had run out or the needle had slipped out causing the forearm to swell. When the saline was exhausted, patients and attendants called the nurse to switch the IV fluid, if she was busy, she would suggest that patients to turn off the fluid flow. Sometimes there was reverse flow of blood into the tubing set. These were perceived as acts of carelessness and neglect on the part of nurse. Asaya said that she would turn off the flow cork when fluid was over following in the nurse's advice, and requested her to change it whenever she came to her bed. She never had fights with any nurse and found them helpful and caring. Both Asaya and her husband added that patients demanded constant personalized attention and care, often ended in the nurse having to give most time to unreasonable patients. It was not possible to attend to everyone then since there were many patients, all of who were equally important to her, even though the patient might be most important and dearest to his or her attendant. She seemed impressed with the fact that

one day a senior lady boss (probably matron) had come to the ward and collected all the papers and examined them. Later she had met all the patients and enquired about their condition. *This* ***mechanism of monitoring and evaluation present in the government hospital offered checks and balances to the treatment process and, was an important aspect which contributed to her good opinion about the government hospital.***

Interpersonal interaction with nursing professionals:

Bishan recognized the multiple roles that nursing professionals performed in maintaining hospital functions in the course of his month-long stay in the hospital for his wife's surgery. His *experience with support staff specifically nurses and ward attendants had not been good. According to him, many nurses used to shout at the patients, more so at the attendants.* ***Many a time, attendants would be scolded and asked to leave the ward****. Most of the reason he gave needed intervention outside the personal capacity of the nurse.* ***To his mind it was because the nurses were stretched with the number of patients each nurse had to take care of****. She had to interact with and face patients through the duration of their stays at the hospital. Doctors usually came for rounds wrote a few instructions, spoke with patients for a few minutes and then they came only at the time of the next round unless there was an emergency.* ***The total number of doctors was high but strength of the nursing staff was small, adding to which the interface of nurses and the patients and their attendants was for a much longer duration.*** *For every attendant his or her patient was very important, so most of them asked for personalized attention and care of the available person, which was the nurse who was usually present in the ward.* ***If the patient was in pain or suffering, the attendants tended to request the nurses for attention and intervention, often time expecting or wanting injections and IV fluids, whereas the nurse could not intervene without the orders of the doctors. Then she was blamed for neglecting the patients****. Some even thought that the doctor might have written the orders but the nurse may either have forgotten about the instruction or was deliberately not giving the medicines to the patients. The constant demands from different patients and their attendants could be responsible for them getting angry at the patients and their attendants.*

Nurses are also in-charge of the cleanliness and hygiene of the ward, apart from the nursing care of the patients. They had get the hospital staff to do the actual work of keeping the area clean, ensure that ***all the supplies were adequate, that rules regarding visiting hours and the***

number of attendants visiting the patients were followed. Most often, the number of visitors exceeded the permissible number. The nurses with the help of the ward boys then had the unpleasant task of getting the visitors to vacate the ward. This was another reason that led them to shout at the attendants and sometimes even the patient. *He further said that most patients and their relatives came from rural areas, their lifestyles being very different, they often did not understand, made mistakes or unknowingly broke the behavioural norms practiced at the hospitals. Several of them,* ***spilt food and liquid on the floor while eating, threw food wrappers on the ward floor or in the corridors or just outside through the window. Many patients and attendants threw the leftover food in the toilets, or out of the windows. This littering was one of the important causes for nurses getting angry and shouting at the patients and the relatives.***

While the doctors merely wrote instructions and prescriptions and left, the task of telling the patient or the attendants to get the medicines (prescribed by the doctors) from outside was the nurse's. They had to face the anger and anguish of the attendants when the latter who expected to get medicines from the hospital, but had been asked to buy them from outside the government hospital. Instances such as those held ample scope for friction between the nurses and the attendants. *Both of the nurse and the attendants, were forced together in a precarious context, resulting in escalating conflict, for reasons that were beyond the control of either party. He said that* ***if the attendants tried and understood the mistakes they were committing and behaved with some responsibility, understood their workloads and the constraints within which the nurses were working then one can understand and accommodate (forgive) the nurse for her display of anger and shouting.*** *He said that* ***their anger and shouting was not an attempt to humiliate or insult the patients and attendants but was a venting of their frustration about their working conditions, work load, infrastructural and institutional limitations****.*

6.1.3 Summary

Table 6.1 Desirable and Un-Desirable Aspects of Experience and Expectation from Therapeutic and Nursing Services

Desirable aspects of experience and expectation from health services	Un-desirable aspects of experience and expectation from health services
<u>Attributes and features of provider</u> • *Praised ANM of the village as she talks to*	• Nurses were often blamed for being rude to patient, shouting at

them respectfully, treats them whenever visited, gives them tablets and injection, and nebulization to their children whenever needed.	them, being careless, negligent and insensitive.
<u>Institutional features – process</u> • *Senior nurse- matron of the hospital doing rounds of the hospital- this* ***mechanism of monitoring and evaluation present in the government.*** • ***As a hospital which offers checks and balances to the treatment process was important aspect which contributed in building her good opinion about the government. hospital.***	
	<u>System structure of health services</u> • Lack of awareness among community of even existence of professions like physiotherapist, occupational therapist, audio-speech therapist and psychology-therapist (counsellor) • Not many experiences of care seeking with these therapeutic professional to understand if and how they contribute to the wellbeing of patients and patient's experiences
	<u>Medical/ clinical care components</u> • Doctor did not inform them about availability and role of such therapeutic professionals. • Non-inclusion of therapeutic professional in treatment process of patient or delay in including them in care process
	<u>Institutional features - input</u> • ***Number of nurses was small***

6.2 Perception of quality relevant to Support infrastructure and services

6.2.1 Experience with other support infrastructure and services

Health care institutions as public places with a sizable number of people using them are expected to have some basic amenities that are functional and well-maintained. Health care institutions provide services to patients with having different kinds of diseases, in differing stages of severity, different levels and types of suffering and pain. Most of the patients and their abilities in performing routine daily functions are affected especially of those who are seriously ill and they need aid and support. Therefore, the other amenities and services provided in hospital have to be in accordance with need of people (patients) visiting there. Hospitals providing indoor admissions, require patients and attendants to stay there for various durations depending on the nature of illness and the treatment process and need the hospital as an institution must be prepared to take care of their needs and requirements.

The health seeking journey of various respondents, especially of hospitalization care often referred to experiences and expectations about basic amenities and services while seeking care. Most of the more volubly articulated observations and experiences pertained to the attendants, however some patients also had to endure poor or inadequate support infrastructure and services. The support infrastructure and services that were mentioned in their care seeking experience included –drinking water, toilets, wash rooms, bathrooms, food and canteen facilities, clothing/ bed sheets/linen for patients, laundry, security, signage, transportation and help. Cleanliness, hygiene and maintenance of hospital premises and all these services were referred to while reflecting on the care seeking experience.

While most respondents focused on clinical care components, they also mentioned the lack of hygiene in the government hospital as compared to private hospital. Experience with support services were often not mentioned by them on their own, however when asked about them, they often time responded with a big sigh. They seemed too tired, and responses were in the vein of ‘don’t even ask what we have gone through, don’t get us started’. The question would elicit smiles among those gathered for the interview; a smile that reflected a shared understanding of what they had gone through. Some said that they had prepared for the hardship they had to

undergo in the hope of cure and relief from the suffering the family member was undergoing. The experience with support services, though not a primary concern, shaped to a significant extent their overall experience of being part of the caregiving and hence affected their wellbeing. The concerns around these support services however also shaped choices of hospitals and care providers, the likelihood of opting for hospitalization, the timing of hospitalization and their ability to sustain the required period of stay in the hospital till the treatment was over.

6.2.2 Sanitation services: mixed perceptions

The acceptable level of cleanliness differed by person as did the expectations around it. The expectations and acceptability of levels of hygiene would also change depending on the nature and type of hospital, especially depending on the patient burden in that hospital. Most of the of the respondents commented on poorly maintained infrastructure and services pointing out dirty toilets and washroom, unclean corridors, stinking wards and bathrooms etc. ***While describing the state of cleanliness at RH Kandhar and government hospitals, Ranpat along with his family members said that government hospitals are so unclean that a healthy person could fall ill there****.*

Recollecting his experience in the operation room Keshramsaid that ***overall the hospital (medical college hospital at Nanded) was very dirty, smelly and was kept in a very bad and unhygienic condition. Every corner had*** **paan** ***and tobacco stains on the walls. There was garbage littered in several parts of the premises. The toilets were very dirty, stinking and in dilapidated condition****. There was lot of scope for improvement in the cleanliness at the hospital. He added that the* ***government hospitals were very dirty, unhygienic with very poor or no maintenance of existing structures. The overcrowding of the institutions aggravated the problem in such a situation. The lack of supporting manpower (human resources for maintaining sanitation and hygiene) and poor work culture among them further led to the deterioration of conditions and made government hospitals unbearably dirty and unhygienic.***

Very old, poor and ill-maintained infrastructure of government hospital building made it a challenging task for sanitation workers too. The overcrowding in government hospitals made it harder to maintain cleanliness and hygiene, the situation only worsening in the monsoon season. *While commenting on the cleanliness and hygiene Bishan and Mayabai More said that the*

hospital used to be dirty and was ill- maintained. They visited it during the rainy season complicating the matter further. Most of the wards and the hospital were dirty and smelly. He also held the people using the services responsible to a great extent for the dismal state of the hospital. While ***hospital staff cleaned the hospital premises twice a day, they put in their effort to keep it clean but the people using the services also needed behave responsibly, not littering the place****. The hospital building needed maintenance since* ***many structures were in dilapidated condition, toilets and bathrooms were in very poor condition. Timely maintenance and painting of the hospital with routine cleanliness would make it more pleasant for the patients admitted. In his opinion there was plenty of room for improvement in the physical amenities at the hospital****.*

Some also felt that the poor status of sanitation services and cleanliness of the hospital was also due to the general lack of a sense of maintaining cleanliness in public spaces among the people. Some of the respondents felt that it was a public place that was overcrowded and therefore bound to have some level dirt and lack of cleanliness. In addition, rural life styles of the patients and visitors, with little experience of living in closed and concrete buildings also contributed to the poor hygiene in government hospital. *Pitamber and Bishan echoed similar concerns in independent interviews. Pitamber further said that most of the patient and the relatives coming from the rural area with different lifestyles tend to commit mistakes and break the norms of behaviour in the hospital and the wards. He said that many patients and attendants spilled food and liquids on the floor while eating. They'd throw the food wrappers on the ward floor or in the corridors or outside from the window. Yet others threw the leftover food in the toilets.* The notions around sanitation, hygiene, the acceptable degrees of cleanliness and acceptable levels change according to different factors like rural/urban location and class. Therefore, many respondents on enquiry said that government hospitals were dirty or had a peculiar smell but those were not big hurdles or impediments as far as they were concerned. *When asked to comment on the overall cleanliness of* ***the government medical college hospital at Nanded, they said that it was not too dirty to stay in. In their opinion there was acceptable level of cleanliness in the wards where the patient was admitted but it did not appear*** **to be a primary concern for them during their stay at the hospital**.

The comparative judgment between government and private hospitals, where the later were the reference point also led community members to see the former as dirty and unhygienic. Nature and type of hospital, patient load, available infrastructure, available human resources etc determined how well can it be maintained. *When asked about the general cleanliness and hygiene Bhagirath told that the hospital was kept clean and neat. While commenting on cleanliness of the wards he said that the supporting staff used to sweep and dust the wards and toilets twice a day. When other people's comments - that government hospital was so dirty and unhygienic that a healthy person could fall ill, were shared with him, Bhagirath said that people who were bound to have different opinions but in his observation his ward was clean and hygienic. He said that government medical college and hospital at Ambejogai was dirty and unhygienic as compared to Ayurvedic hospital at Nanded. He again expressed his satisfaction with the overall experience at the ayurvedic hospital and said that if at all if he needed any further treatment he would choose to go to the ayurvedic hospital at Nanded.*

*Asaya and her husband c****ontradicted the popular perception that government Hospitals were very dirty and unhygienic. She said that the supporting staff cleaned and mopped the hospital ward twice a day and mopped it two times with medicated liquid solutions. She said that there was no dirt or garbage in the ward; and that the wards were cleaner and more well maintained than many households in their area. She added that nurses changed the bed sheets regularly and ensures that the patient's bed was kept clean.*** *They echoed the popular opinion that* ***hospital and ward had a distinct smell, but that according to her was the smell of medicines and chemicals used for cleaning and mopping*** *and further added that many people did not like that smell.* Support services like linen and sanitation were appreciated by some respondents while there were many who were very critical about sanitation and upkeep in government hospitals.

6.2.3 Food

Many of the comments on cleanliness of government hospital were based in general on popular opinion, some based on their experience in the OPD and emergency services and others based on short or long hospitalization experience. Some respondents did not complain about cleanliness of government. hospital and mentioned that it was maintaining decent level of hygiene. There was

appreciation to the efforts taken by sanitation staff of the hospital in cleaning and mopping hospital wards, corridors and washrooms twice daily. There was lot of appreciation for food provided to patient from hospital by many respondents who were admitted in medical college and district hospital as well as ayurvedic medical college. *She (Asaya) added that* ***treatment from the government hospital was accompanied by sumptuous breakfast, lunch and dinner along with tea, milk and fruits. This was a valuable service specifically for poor patients from rural areas or those who did not have their home or close relatives in the Nanded town. It saved lot of money and inconvenience involved with arranging food for the patient.***

Free food provided was a very decisive factor in even people even daring to seek care or even in their decision to choose in-patient care for illnesses that required long periods of hospitalization. Food availability was one of the very important considerations behind choosing government hospitals for long term care requiring hospitalization. Asaya was very impressed and expressed her gratitude to the food provided from hospital during her stay at the hospital. The food provided was according to the need of the patients. Bhagirath and Pitamber mentioned this as one of the important reasons for them to opt for treatment from the ayurvedic medical college hospital.

6.2.4 Water

Basic and essential services like access to safe drinking water made a lot of difference to their experience of care seeking. *Ganraj's wife recalling her experience as an attendant when her husband was admitted to a hospital said that she had to go from one corner of hospital to the other to get drinking water (cold water during summer), and as a woman it was difficult for her, especially if she needed to get water at odd hours.* Therefore, in addition to just making facilities available it also mattered if they were easily and conveniently accessible to most of the users.

6.2.5 Special toilets for patients with special needs

While complaints of hospital toilets being broken or dirty and inadequate in number were oft repeated, Shambhu's experience, as a paraplegic patient made the issue of basic support services very sensitive and important needing greater attention and care. *He recollected that t****here was some mobile toilet unit in Ayurvedic hospital but it was not in use. In the absence of that***

mobile toilet or lack of toilet as per the requirements of a paraplegic patient made him go through lot of hardship, indignity and suffering on daily basis. He needed two persons to hold him therefore he had to keep at least one attendant with him round the clock with a hope that some of the hospital staff would help him too. This need for an attendant contributed to increasing the cost of care as well as resulting in difficulties at home since his wife had to leave behind his elderly parents and small children.

Patients have to use toilet facilities daily and most of the time these facilities are shared and are not designed to meet the requirements of the wide range of patients who receive in-patient care at the hospital. Patients had to deal with inconvenient, ill equipped and poorly maintained facilities daily. Paralysed patients or those with limb fractures or were severely weak would require attendants to help them their daily ablutions. This constant need for attendants was one of the important impediments in care seeking, especially for those requiring long term hospitalization care. For an objective evaluation of quality, cleanliness and maintenance of toilet would form an integral part of the quality evaluation process, but toilet design to meet the special needs of differently abled patients would not be captured merely through evaluations of hygiene.

6.2.6 Clothing and linen

In addition to scarce resources in government hospitals for providing clinical and support services there also seemed a lack of commitment to providing support services that would give patients comfort and offer them a dignified stay during hospitalization. Either these support services were not considered important or were simply neglected. Sometimes even available resources would not be used to make sure patients received these support services. *Recalling an incident from his long stay in the Ayurvedic hospital, Shambhu said that there was once a* ***visit by a squad from Delhi for which the whole hospital was spruced up, patients' bed sheets were changed. All patients were given clean white cotton clothes to wear and clean white bedsheets, all of which were promptly taken back from the patients as soon as the squad's visit was done with.*** *He wondered if the clothes were meant for patients, why they were not given to them. In his opinion there was a* ***tendency in medical personnel at government hospitals to withhold resources from patients despite their availability.*** *He speculated that, doctors at these*

institutions may be showing fake laundry bills but pocketing the money for themselves. He also complained about a mobile toilet that was not opened to the paralyzed patients even.

6.2.7 Private sector support services

There were a lot of opinions about hygiene and cleanliness of government hospital and other support services like food provided to patient. The care seeking journey of patients from private hospitals also brought out issues related to support services. Some of these issues were common to the government sector hospital as well. *Ranpat had been his wife's attendant at* ***private hospitals on two occasions in two different towns. He had to sleep in the corridor, on the floor****, something all attendants knew that they would have to* ***sleep either in the corridor or in the verandah or outside the hospital on the roadside or on the pavement. This was not the only inconvenience. People had to get their food from home. Someone would have to send the food from home. Or they had to depend on hotels where nothing other than snacks was available, not to mention that*** *buying food from outside everyday was very expensive. F****amily members attending to the patient also did not have proper amenities for bathing, or toilets. Some of the attendants were without a bath for the entire duration of hospitalization. Family life back at the home was completely disturbed with no one left behind to take care of the elderly grandmother, in her 80s and other two small children. Work in their family-run farm was completely suspended and the agricultural fields had to be left behind unattended, at the mercy of the goodwill of fellow villagers and neighboring farmers.*** Being from a relatively well-off farming family, they did not have to worry much about the loss of wages and the cost of living. However, it would have been very difficult for others especially for the poor and wage labourers. Concerns around these issues had made Bhagirath, Pitamber seek care from government hospital.

Tanaji while comparing the experience with support services from the government and private hospitals said government *hospitals offered very important non-medical services like the provision of linen, clean bed sheet, support manpower, transport for referral and the all-crucial food for the patient. Provision of food from the hospital took away a huge burden for the attendants. It took the treatment experience to a different level specifically for those from far way rural areas. If the patient was from a really poor socio-economic background, provision of food*

proved to be a crucial support for the family of the patient. Even for those who could afford to get food, struggled to invest time and energy in arranging food for patient with their limited knowledge of the patient's dietary needs, while meeting the demands that the treatment made compounded by the situation of vulnerability and precarity in an unfamiliar city.

6.2.8 Attendants: Necessity and needs

Attendants may be needed with patients for various reasons. Foremost being physical and emotional support to the patient during hospitalization. Various critical decisions during the care process need the support of and deliberation with family members and their presence may be crucial for a person in pain or experiencing debility. Minor patients may not be able to do without attendants. The physical labour of running errands, following institutional procedures like paying fees, buying medicines from the market when unavailable at the hospital and coordinating with various departments would require attendants especially in hospitals that have no support staff. In the private sector especially, all medicines and consumables needed are to be purchased on a daily basis. There are several tasks that attendants have to perform in the government sector- filling up forms during different investigative and interventions, giving consent, transporting weak or bed-ridden patients to other OPDs for opinions of experts or to diagnostic centres for investigations, fetching water and food and feeding the patient, helping the patient use the toilet, change position, sit and walk during the hospitalization period etc. requires some attendants with patient during hospitalization period. Nature of illness along with the ability of the patient, existing institutional processes and availability of support staff to help the patient in above needs determines the number of attendants needed.

Both government and private hospitals with their institutional processes and meagre availability of support staff needed more attendants to be present to help patient. Neither settings made provisions to make hospitalization convenient. *Responding to a question on the limitations and shortcomings in the services provided at the government hospital, Tanaji said that apart from other difficulties and problems, if* ***provisions for the stay of attendants could be made, the services would be more useful. At least two attendants were constantly needed with a patient, according to him. One with the patient and another for running errands, or for taking the patient to different departments for investigations and opinions of different experts or to fetch medicines and material from outside.*** *Hospitals required, unless it was impossible,* ***at least one***

of the relatives to be with the patient in case if a medical emergency or for obtaining consent or to explain the progress and future line of treatment*. The hospital did not have any* ***accommodation facilities for attendants of the patient****. In some cases, an attendant was allowed to stay with the patient for the initial few days.* ***Most of the time male attendants were needed for running around and to make the necessary purchases*** *or make decisions about the future course of action in treatment. However,* ***male attendants could not be very helpful since their movements would be restricted in case of female patients in the female ward.*** Hence, the gender of patient also affected the number of attendants needed.

In most of the cases and when patient became relatively stable most of the attendants are made to go out of the ward. If there was more than one attendant, then they are thrown out of the hospital premises. ***Most of the times attendants had to spend their nights either in some corridor and corner of the hospital or outside the hospital on the footpath right in front of the hospital****. With no provision of appropriate canteen for the hospital visitors* ***they had to depend upon street food****. The routine activities like* ***toilet, bath, brushing teeth become a luxury****. They had to arrange these things in some of the hospital toilets. Many a times it was not possible to take bath for few days.*

6.2.9 Security and arrangement for stay of the attendants

People were also vulnerable condition to attacks by the local small-time thieves and thugs. *Bishan was carrying some* ***money and jewellery, a total of 15,000 Rs. somebody stole this money and jewellery during their stay in the hospital from him.*** *This was a major blow to the family. This* ***need for facilities and arrangements for the attendants and visitors of the patient was*** *echoed by many other families in the village.*

Keeping attendants along with patient in distant town has financial implications too. More attendants meant additional expenditure on their food and stay, greater indirect costs due to the wages lost. The absence of family members whether patients or attendants (attendants were usually functional adults from the family) affected the functioning of families, particularly when they were at far away distant towns. ***In all hospitals that Shmabhu had sought treatment he had to have two attendants all the time. As a quadriplegic he could not move and to help him in his movements he needed two people of his own. This constant need for two attendants had***

increased the total costs of care. *When asked about* ***help from the hospital staff, the ward boy/ ward assistant he said that in government hospitals, none of the staff helped patients in these aspects.*** *In the* ***trust hospital Tayar, the staff strength was low and the workers were underpaid so there was no question of help****. However, while commenting on this kind of help in private hospital he said that* ***in private hospital, the patient would even be provided with a bedpan for toilet and these pans would be then taken over, and patients would be charged for them. He then acknowledged that he did not have any personal experience of his own as a patient in a private hospital.*** *He recollected that there was a mobile toilet unit in Ayurvedic hospital but it was not in use. With no help for basic daily ablutions he needed two persons to hold him, and that had contributed to increasing his cost of care as well as family disturbances.*

The requirement for attendants and its financial implication and effects on rest of the family affects many decisions during the care seeking journey including whether care will sought or not, the institution where care would be sought and for how long. *Shambhu got discharged from the Ayurvedic hospital after three months of treatment, even though the doctors at the hospital wanted him to stay for some more time, may be for a month or two.* ***However, at his request and he was discharged because of his family circumstances. His hospitalization needed someone to stay with him constantly and his wife was staying with him. There was no one at home to take care of his children and his elderly parents. His family was disturbed and in disarray with his hospitalization for such a long time at the district town. Most importantly the cost of living there with one attendant was very high.***

Reflecting on their experience at government medical college and district hospital Asaya and Madhukar *said that nothing could match the treatment at the government. hospital. They said that government hospitals don't exploit and rob the patients like private ones. Rational treatment was offered free of cost or with minimal charges.* ***The government hospital services, he said, are to some extent inconvenient where one or more attendants are needed, given its nature of service delivery but there is no arrangement and facility to accommodate the patients' attendants. These attendants have to sleep in the corridor or on the pavement and footpath outside the hospital. They wished that there were some arrangements to make the attendants' stay convenient.***

The need for attendants can be questioned and the number of attendants required could be cut down significantly by improving the paramedical worker strength along with number of supporting staff and by cutting down the medicine and supplies needed from outside the hospital. If government hospitals build trust and faith in the community and improve their brand image then the number of visitors and attendants would go down as they would be confident of getting appropriate and humane care from government hospital. There will still be a need for attendants who provide emotional support and help with decision-making about the line of treatment. These attendants need to be provided with appropriate facilities to stay as they will not have any support structure in faraway district headquarters. Absence of support mechanisms in hospitals for attendants, and inconvenience associated with receiving services pushes patients to private sector which offer some albeit meagre convenience and amenities and quick services thus cutting on the duration of treatment. If the private services are unaffordable then the inconvenience of government institutions acts as a deterrent in seeking care, till complications arise or adverse events crop up. This probability of no treatment or delayed treatment is high if the patient is a woman, elderly or disabled person as they would need more attendants, even if services are free.

6.2.10 Summary

Table 6.2 Desirable and Un-Desirable aspects of experience and expectation from Support Infrastructure and Services

Desirable aspects of experience and expectation from health services	Un-desirable aspects of experience and expectation from health services
<u>Institutional features - input</u> • Availability of support infrastructure and services like– drinking water, toilets, wash rooms, bathrooms, food and canteen, clothing/ bed sheet/linen for patient, laundry, security, signage, transportation and help. • Support services like linen and especially food contributed immensely in positive experience of services provided from government hospital. • ***Nice and sumptuous breakfast, lunch and dinner along with tea, milk and fruits. This was a great thing for the patients specifically for poor and for patient from rural areas or all***	• ***Lack of supporting manpower (human resources for maintaining sanitation and hygiene) and poor working culture*** • ***Many structures were in dilapidated condition, toilets and bathrooms were in very poor condition. Timely maintenance and coloring of the hospital with routine cleanliness will make it more pleasant*** • Very old, poor and unmaintained infrastructure of government hospital building

patients who don't have their home or close relatives in the Nanded- saves money and adds convenience	
<u>Institutional features - process</u> • Cleanliness, hygiene and maintenance of hospital premise and all these services was referred to while reflecting on care seeking experience. • *Non-medical services which takes the experience of the health services beyond the medical treatment services to make it feel like care services were services like food, linen, transportation. In the private hospital such support services were not available.* • *these non-medical services include provision of linen, clean bed sheet, provision of support manpower, transport for referral and very important and crucial of these is the provision of food from the hospital*	• Poorly maintained infrastructure and services pointing out dirty toilets and washroom, unclean corridors, stinking wards and bathrooms • ***Government hospitals are so unclean that some healthy person might get illness there.*** • ***Very dirty, unhygienic with no or very poor maintenance of the existing structures. The overcrowding of the institutions with no maintenance*** • ***Hospitals unbearably smelly, dirty and unhygienic institutions.*** • Inconvenience- no or delayed treatment is high if patient is a woman or elderly or disabled as they would need more attendants, even if services are free.
	• **<u>System structure of health services</u>** • *Paralysis patients or patients with limb fractures or severely week patient would require attendant helping patient in their daily activities of using toilet and support staff was not provided in patient care.* • Attendants-***sleep either in corridor or verandah or outside the hospital on roadside or pavements. There was inconvenience in getting food. They used to get their food from their home, someone from home used to send the food from home. Regular food apart from snacks was not available in the hotels there.*** • *Hospital does not have any* ***provision for the stay or to accommodate the attendants of the patient.*** • ***There is no arrangement and facility to accommodate the attendants of the patients. They wished that there were some arrangements to make stay of attendants convenient.***

	• Number of attendants required can be cut down significantly by improving the paramedical worker strength along with number of supporting staff and by cutting down the medicine and supplies needed from outside the hospital.

Chapter- 7 Affordability, Comparison of Public and Private Services, Discrimination and Suggestions for Improvement

7.1 Perceptions of Quality of Experience with the Cost of the Care Provided

In their care seeking journeys, the cost of care to the patient was the second most important concern, according to the community, right after the concern about cure or relief from symptoms. The concern for the cost of care played out at every stage of care seeking and was an important dimension of their evaluations of most healthcare-related experiences that they had. It was quite often that one heard grievances such as '*despite spending so much money, we did not get relief from the symptoms*' or 'the *doctor did not explain to us about the nature of illness'* and '*we had to sleep in the corridor of the hospital while the patient was admitted'* were common. There were also expressions of satisfaction like '*we got big surgery and relief from symptoms by spending a nominal amount* 'or '*yes, the hospital was dirty and overcrowded, but it provided free services'*. Nearly all community members had statements that connected the experience of recovery or lack of relief and the hardships undertaken in the care seeking journey with the money spent. This shows that cost of care was of primary concern in the assessments of their care seeking experiences. For the rural agricultural community, primarily from the economically backward region of Marathwada, affordability of health care services was an important concern. The mostly landless 'Mang' and the agrarian 'Marathas'(with a large number of marginal farmers) expected health care services to be effective in delivering the intended result and expected these services to be available free or in a manner that would not entail much expense. These two primary concerns of getting relief from illness and cost of care were also very closely related to each other. Illness and suffering cause loss of productivity and income; therefore, the experience of the illness itself involves cost. The nature of illness in the form of its severity and duration also affects the loss of productivity and income. Care seeking for relief from symptoms has its own costs. Nature of care also affects the cost of care through various mechanisms based on the time taken to relieve suffering, whether it offers complete or partial relief, and the side effects and complications incidental to the care given. The difference in health care provisioning arrangements in the form of public or private; the location and distance of the institutions that provide health care services, the level of expertise in assessment and intervention that they had; pricing structures and financing mechanisms all affected the cost of care. During their care

seeking, patients have to incur some direct (paid directly to the health care provider, for medicines, investigations, transportation etc.) and some indirect / opportunity costs (productivity and wage loss of patients and attendants during care seeking).

Concerns of the direct and indirect cost of care were constantly articulated by most of the respondents. These concerns shaped their care seeking journeys through various pathways- if and when to decide to take health care, the choice of health care providers, health care institutions chosen, clinical interventions chosen and opted for and the way they evaluated outcomes of their care process as well as their experience with the entire journey of care seeking. Some of these concerns about cost expressed by them at every stage in the care seeking journey and the ways in which the cost-of-care lens shaped their evaluation of that experience have already been discussed in the previous chapter. This section briefly discusses some of the additional concerns around the cost of care shaping their perceptions of quality in health care.

7.1.1 Routine OPD consultation and investigations.

Utilising health care provided at the PHC in Panshevadi did not cost community members anything. GPs from Kandhar town were most commonly sought for seeking care. The public transport available for Kandhar town was a state transport bus once a day and private auto rickshaws running every 45-60 minutes, charging INR 20 for one-way travel. The average consultation fee charged by GPs was between INR 100-150. The average cost of medicines was between INR 300 to INR 600.

The second often-used destination for seeking care was Nanded, located at a distance of 70 KM and required INR 80 for one-way travel. Travel within the city of Nanded was different based on the distances within the city by auto-rickshaw. Specialist consultation charges ranged between INR 300 and INR1000. Cost investigations and medicines varied. When Ujala sought care in a private hospital *in the gynaecology OPD for treating white discharge and heavy bleeding during the menses, she had to incur a cost of* INR *1500 for an initial consultation and subsequent costs for a follow-up consultation with test results. She was advised to get a USG of the abdomen and pelvis along with blood and urine tests and was charged INR 800 for the blood tests. She visited again with the USG report when the* ***doctor advised a hysterectomy, the charges for which she said were about INR17,000-18,000. Even though she advised an operation and was informed***

of its charges, the doctor did not give her a diagnosis or explanation for what condition she needed the surgery. Ujala and her family spent INR 1500 for this advice from the private hospital. Since she did not have that much money to spend on the surgery, they could not think of getting the operation done. Thus, this prohibitive cost of the operation caused them to decide to live with the suffering.

Asaya, who was treated for a poisonous snake bite at the government medical college hospital and discharged with advice for follow-up visits, had developed large oedematous and patches with no sensation. They were worried about her foot and that they still had some residual poison. Dr. Shende of Muked, the neighbouring block town, assured them that there was no poison left in her body but added that her condition, specifically of her foot, was serious and told them that it would need immediate attention. He gave them the address of a doctor in Nanded and advised them to visit him for an operation on foot. ***After surgery, he said that she would need frequent changes in the wound dressing at Dr. Shende's hospital. A full treatment would cost them around INR 25,000.*** *If it did not help in getting the wound healed, she would need a different operation at Nanded where the doctors would require grafting the skin from her thighs onto her wound. The follow-up visits and wound dressing could then be done in his hospital at Mukhed. He further told them that if the skin on the thigh also did not help in healing the wound, then she would have to undergo amputation of her foot. They paid INR 100 as a consultation charge and were left scared by the string of operations he had suggested to them. The potential expenses worried them greatly, given that their economic condition would not allow them to foot the bill even for the first operation, which was costing at least INR25,000- INR 30,000. After exiting the doctor's cabin, they sat troubled and hopeless in the OPD for some time. After some advice from people, they sought treatment from the traditional healer who was not charging her anything. While reflecting on all three experiences, Asayasaid that she had to pay only INR150 for medicines for a five-day in-patient treatment for a life-threatening poisonous snake bite at the government medical college hospital. The cost of getting free treatment from the herbalist in the adjoining village was also around INR 150- the couple's travel expenditure over three visits to the traditional healer in the adjoining village. And merely for the advice of getting an operation from Nanded, Dr. Shende had charged her INR 150!*

7.1.2 Free services from a government hospital

The experience of seeking care from RH Kandhar was evaluated as unsatisfactory by most of the community members. On enquiring about their preference for paid consultation, GPs over free services from RH Kandhar many respondents said that services from the RH were not free. *Krishna's uncle said the doctors were, most often than not, never available immediately. They came late, would not examine the patient properly, and would not talk to the patient or the relatives properly. The treatment would be delayed and when started, would rarely be given with sincerity and or care. Most of the time the required medicines had to be purchased from outside. So, in his view care, given in the government hospital was also not free.* Many respondents from the village expressed this sentiment.

7.1.3 Hospitalisation expenditures

Hospitalisation usually entailed heavy expenditure. Community members generally went to Nanded for hospitalisation, and the long-distance added indirect costs to the health care expenditure. The block town that was closer, offered in-patient facilities only for MCH services in two small private nursing homes, both run by gynaecologists and one of whom had a paediatrician spouse.

At the time of admission, usually, there was a discussion on the tentative expenditure that the hospitalisation would entail. The hospitalisation costs were at times negotiated by requesting doctors and sometimes by pleading with them about their very difficult financial and personal circumstances. *Dr. Adhav, who examined Sulekhahad said that he would try to ensure a normal delivery for her. Later in the evening, he told them that she would need a caesarean section. Her father-in-law negotiated with the doctor to agree on INR13000, bringing down the cost from the INR 15000 that had been demanded initially. The* ***price was negotiated*** *before the start of the operation, which was conductedat around 9 pm.*

The prices quoted were tentative and included only consultation and hospitalisation charges for a fixed duration. The patients were told that they would have to buy medicines and other consumables as required that the hospital would use as per requirement. These medicines and consumables also had significant costs that had to be paid at the pharmacy. In Sulekha’s case, the *cost of the operation, consultation and hospitalisation for seven days was INR13000; medicines*

and materials like syringes, needles, and gloves had to be bought from outside, and their cost was over and above the INR13,000. This ***cost break-up*** *and quotation were a bit misleading since they gave an initial impression of a lower cost than what one eventually ended up spending.*

A major portion of the hospitalisation cost was for consultation and regular monitoring of the patient done by doctors, the rest pertained to the charges for the bed. Nayan shared this experience of hospitalisation of his new-born grandchild.

After some time, Dr. Khure came back, assessed the baby, and informed them of his poor condition. He also accused them of having been negligent of the baby. After the operation at Dr. Adhav's hospital, finishing work at their own hospital, they had been tired and went to sleep because of which they could not monitor the baby well. He told them that he had last seen the baby at 4 am in the morning when the baby was well, but somehow his condition had worsened and he asked them to take the baby to any other hospital they wished to pick. ***Nayan then told him, 'You refused us discharge when we asked for it, now keep the baby admitted in your hospital, but if something goes wrong with the baby then be ready for the consequences'. He had asked for the baby in the morning at 9 am, and Dr. Mrs Khure had told them to take the baby away at 1 pm. Before leaving the hospital, he told Dr. Khure that he was ready to pay whatever it cost but would not take the baby until it recovered. Then he, along with his relatives, left for Dr. Adhav's hospital, where an attendant from Dr. Khure's brought the baby and handed him to them along with a bill of INR3000. They paid the bill and took the baby, having to*** pay even for negligence.

7.1.4 Economics of seeking care- prompt and potent medicine saves the cost.

Relief from suffering as early as possible was the primary concern when someone fell ill. The logical approach was to get relief most conveniently at the least possible expense. These concerns were affecting their choice of healthcare providers and institutions and they tried to balance the expenditure on treatment against the possibility of getting relief from suffering. *Vithoba reflecting on his experience with both government and private providers explained that prompt treatment with* ***high-end medicines not only reduced the total duration of illness but also cut down on cost. One saved on indirect costs*** *since prompt treatment meant reduced*

complications and fewer visits to providers, whether to try out multiple treatment modalities or medications or for follow-up. It reduced the duration of illness and faster treatment with better medicines that gave quicker relief and less suffering. Shorter durations of illness also meant cutting other losses like wages foregone due to an absence from work. Hence Vithoba asserted that given its lower indirect costs, prompt and effective care was the care that was economical. The chances of getting prompt treatment with high-end medicines were generally higher at private hospitals. Thus, many a time the total costs for conditions that did not require hospital admission would be lower in private clinics.

Commenting on experience at the district hospital, **Nayansaid that for minor and less serious conditions, one could not afford to spend the whole day in the district town**. The district hospital involved a lot of running from one room to the other, deciphering the maze of departments in different buildings. One had to start very early from home to collect the necessary OPD paper or end up missing it altogether and having to return on another day. It also meant standing in long queues everywhere to obtain signatures of doctors, appointments, investigations, medicines and procedures etc. **The procedure was often not completed in a single day since some departments did not open daily, or appointments were not available on the same day.** If one was lucky, then it would be possible to be done with the treatment in a day, but that invariably meant a full, whole day, sometimes being stranded in the city without any means to get back home the same day. Even after the ordeal, one could not be sure of meeting a polite, humane doctor who would examine them thoroughly and provide treatment that would result in relief. **For logistic and financial reasons, they preferred that everything be completed by early evening so that they could go back home by the last auto rickshaw that plied between their village and Kandhar town. This was why they preferred private hospitals, where they could avoid no bureaucratic procedures. The necessary investigations and treatment could be finished the same day, or else the doctor would at least provide treatment as a stop-gap measure**.

7.1.5 Comparative cost estimates

Reflections on the cost of care usually evaluate the money spent on the care seeking journey, with reference to specific categories of healthcare. If the expenditure was incurred in a private hospital, the community member would comment on how they could have saved if those services

had been provided at a government hospital. If the expenditure was incurred in a government hospital, then there was some sense of satisfaction at having managed to save money or avoid indebtedness. On asking which hospital he would rate better, Keshram clearly stated that government hospitals were better. *First and foremost was the economic consideration.* ***The same procedure (removal of a mass from the neck)in the private hospital would have cost him around INR 6000. This was a huge amount of money as compared to an almost free treatment that he got at the government hospital.***

Bishan and Mayabai were happy about their experience from the government medical college hospital for having gotten surgery fora fraction of the cost compared to what was suggested at a private hospital. *After going through the USG report and after examining Mayabai, Dr. Bawadekar told them that she had gallstones that called for* ***surgical removal of her gallbladder, within a window of fifteen days, at a total cost of INR 18,000-20,000.****He added that if they did not want to be operated on by him then they could have to go to Hyderabad or Bombay for further treatment. Mayabai got an endoscopy, was treated for her heart condition and had her gall bladder removed at the government medical college hospital - all three at a nominal cost as compared to the* ***INR 18,000-20,000****that the private hospital had quoted. At the government hospital, they were reassured that they did not have to spend much money for her treatment. Most of the medicines needed were provided from the government hospital, and very few medicines and materials had to be purchased from outside.* ***The total money spent on buying medicines from outside was about INR 300-400, while food for the patient was provided from the hospital. They only had to spend on travelling and food for the patient's attendants, which they would have incurred in the private hospital as well.***

7.1.6 Cost-benefit expectations

The cost of the care was an important consideration affecting the decision of whether to seek care or not. Delaying care or avoiding it was possible in certain kinds of illnesses. Life-threatening illnesses did not give much room for not to seek care, though there were also people who had died due to lack of money for treatment. In such a situation, if lives were saved, major disabilities avoided, or long-term pain was relieved, then the cost incurred on care was somehow easier to bear. Ranpat's *baby was admitted to Dr. Panwar's hospital. Before admission, the family had sought reassurance from the doctor, asking him whether it was*

possible for him to treat and cure the baby's condition or else he would take the infant to Nanded, the district headquarter, for further treatment. ***Dr. Panwar had then assured them of a complete cure. He, however, also told them that it would cost them more and asked them to be ready to spend money. They agreed to spend the money if the baby would be assured of a healthy and normal life.*** *Once admitted, the infant* ***was given daily injections for seven days- one costing INR 1400 in the morning and another priced INR 1100 in the evening.*** *The medicines were bought daily, and the c****ost of care at Dr. Panwar's hospital was around INR 26,000, which excluded the cost of medicines and other consumables. The family was eventually happy and relieved when the infant recovered.***

Circumstances and experience had forced them to get used to not seeing or experiencing recovery despite the fact that treatment advised by the GPs and their usual response to this lack of relief was changing the provider/doctor. Failure to recover or experience the desired improvement was very traumatising for people with serious or undiagnosed conditions. They felt exploited, especially when the cost of care was huge. After their experience of trying to get G*anesh treated, his family was left feeling cheated and exploited. The disappointment at the lack of improvement in Ganesh's condition post his traumatic stroke, and hemiplegia was only compounded by the doctor and the hospital's behaviour towards them. At the time of this study Ganesh was living with several contractures on his body and was suffering from disturbed speech, despite spending more than INR 200,000 on his treatment. They were disappointed with the medical advice they received from the neurosurgeon who had admitted Ganesh for a month and felt that the doctors fleeced them till they realised that the family had exhausted its resources.*

7.1.7 Forced expensive care

People enquire about the tentative expenditure that treatment may call for and make choices in accordance with their own paying capacity. Despite their attempts to ascertain the tentative cost of care, sometimes things did not work out as had been agreed upon. In some instances, the lack of alternatives forces people to explore available options of care despite knowing that it would be catastrophic for the family.

Families could deal with small revisions in the tentative cost negotiated and quoted to them, but large fluctuations could sometimes prove unsettling for the entire family post-treatment. *Ranpat's uncle had swelling on his neck, for which he consulted a doctor in a private hospital at Nanded. After some investigations, which included an FNAC test, the doctor informed them that the swelling was cancerous and needed an operation that would* ***cost them around INR 15000 and would*** *ensure a complete cure from the disease. The family decided to get the surgery performed at the said hospital. After the operation he was admitted for a few days, and the* ***total direct cost of care came to an unanticipated amount of about INR 55,000. They were then forced to sell off some of their land to pay the hospital bill.*** *Within a month of the operation, the patient developed multiple nodules at the site of surgery and died within two months. The family felt that the doctor had not advised them properly and nor had his treatment been effective. They felt that the doctor should have informed them and referred them to the appropriate institution if the case was beyond him. The patient had lost his life* ***despite the huge sum of money spent****. At the time of this interaction with the researcher, they said they still wondered what the prognosis would have been, without the operation, or if they had visited a different hospital, at a higher level.*

The lack of alternatives sometimes pushed people into choosing a particular healthcare option despite being aware of its high costs. ***Paraplegic Shambhu spent twenty-two hours at the government medical college hospital in pain, hoping to be treated and have his sore bed ulcer dressed. He was denied both outpatient care for his ulcer and admission at the Ayurvedic medical college. With no government hospitals showing sensitivity to his suffering, he was forced to spend a day on the street and left with no option but to resort to a private hospital. Given that he could afford to spend very little, he opted for*** *Tayar Hospital-****a trust institution that ran on a no-profit-no-loss basis****. Here he was admitted for a month and diagnosed with sinus. They dressed his ulcer regularly and gave him some medicines and antibiotics. Despite his lean finances, Ganesh had to spend almost INR 20-30 thousand at the hospital for medicines, stay and food for himself and family members attending to him. During this stay, that was a month and two weeks long, his family was repeatedly in disarray, with the children's schooling and his parents' health getting affected since there was no one to take care of them.* ***He had to sell off a part of his land to meet the expenses of this treatment. He further went on to say that if the government doctor had shown the courtesy to treat him, his land, the only source of***

livelihood for the whole family, would have been spared. The expensive care that was forced on him was due to the insensitivity and irresponsibility of government Hospitals which had pushed him into severe poverty. His tragic and unfair experience of impoverishment was clearly due to the denial of care by the government hospital.

7.1.8 Partial care /incomplete treatment

Limited economic capacities could force people to abandon treatment midway, even before they experienced relief if the care was relatively expensive care. Levels of poverty could be such that many people find the indirect costs associated with free treatment unaffordable. *Shambhu got discharged (against medical advice) from the Ayurvedic hospital after three months of treatment, even though the doctors had wanted him to stay for a month or two more. However, he requested the doctor for a discharge because he also needed to think of his family's needs. His hospitalisation required someone, in this case, his wife to stay with him constantly, which increased their* ***costs, especially by way of very high food expenditures.***

7.1.9 Delayed or no care due to resource constraints

Several people are priced out of medical care. *Pitamber had tried taking treatment for the weakness in his limbs due to spondylitis. He had approached various specialists and exhausted all his resources, after which he tried getting treated at the Ayurvedic medical college, where he felt cared for. The doctors made a sincere effort to take care of him and treat his illness but there the improvement was not significant. He had recently heard on the radio that there was a specialist who treated such conditions. At the time of this study,* ***Pitamber was saving money so that he could consult that specialist doctor****.*

Sometimes the cost of care being prohibitive forced patients to live in suffering. *Ujala's was advised hysterectomy by Dr. Trishila who said she would charge around INR 12,000 for the procedure Ujala expressed her inability to organise such a huge amount of money in a short period of time. She finished the month-long course of treatment that gave her very marginal, partial symptomatic relief. She continued the same medicines for six months, buying them from the market, after which she gave up on what she thought was a futile expenditure on useless medicines. She consulted doctors at another private hospital where she was once again advised a hysterectomy for a charge of about INR 18,000****. The family could not even afford to think of***

collecting the money for her surgery since they were sure that they had no option but to borrow from private money lenders at high-interest rates. Hence, she decided that surgical treatment was a luxury she could not afford. According to her, there was no point in taking a loan to seek happiness by ridding oneself of physical suffering. She had two daughters to be married, so there was no question of her getting a loan for her treatment. She had no option but to live with the suffering and make do with some treatment from the PHC or from the private clinic at Kandhar whenever the physical pain and discomfort got severe or unbearable.

7.1.10 Indebtedness

Purushottam had a sense of achievement of saving his child on the one hand, and on the other, the painful journey of repaying the huge debt that lay ahead worried him. *Purushottam Waghmare had to spend around INR 12,000 to get his infant treated for cough at the Marathwada Children's Hospital. He had borrowed the sum from a private money lender and was paying it back at the time of the study. He characterised the experience at the Marathwada Hospital as good because his baby had recovered from illness.* In some cases, the large bills accruing from hospitalisation were also a cause of some pride for the family, at having spent or being able to spend that much money to care for their own. Thus, while the attempt was to save money, at the end of treatment, there was some pride in being able to show 'we care for our family', and if outcomes of those large expenditures were not as desired, then there was the solace that, 'we haven't faulted in our attempts to do everything, we could have; we have spent so much money on the patient.' Thisway of thinking about healthcare expenses was found to be common in interactions with different respondents.

Hospitals and doctors providing affordable and accessible care had immense value and importance in the lives of the community members. These attributes of doctors and hospitals were preferred over the qualifications and knowledge of the doctor. *Madhukar reflected on his past experience of getting treatment from government hospitals where he did not have to pay any money. His wife's life could be saved after a poisonous snake bite was treated with a five-day hospitalisation. Though he had tried to get treatment from Dr. Shende's hospital ,his (the doctor's) unavailability forced him to go to the government medical college and district hospital, Nanded. He later consulted Dr. Shende to get his opinion, a final word on the case, since the latter was known for his capabilities in treating snake bites. He advised a set of operations, with*

an initial procedure that would cost around INR 25,000. After the visit, ***Madhukar wondered how much the doctor would have charged them for that life-threatening condition at that critical point. Going by what he had suggested for treating the wound, the couple estimated that they would have had to shell out almost one lakh if he had treated her snake bite. Madhukar believed he was very fortunate that he had to go to the government hospital where her life was saved without paying any money for treatment. He added, 'Dr. Shende might be a great doctor and a specialist for treating snake bites, but he surely is not a doctor for and of the poor people.'*** *After his experience with Dr. Shende's hospital Madhukar believed that 'poor persons should not even climb the steps of his hospital' for it was a very expensive hospital.* ***His wife added that 'if somebody is going to seek care at that hospital, then he/she has to be ready to sell off their homes and land'.***

7.1.11 Suspicious practices/ malpractices

During the care process, if people felt any doubt about the intentions of providers and the appropriateness of practices followed by the health care provider, then people chose to change the way they were seeking care or the provider they were approaching as early as possible. Such experiences were remembered as shocking and bad experiences in their care seeking journey. Sometimes doubts about suspicious practices emerged during the care process; at others, suspicions about the care process came up retrospectively while reflecting on the care seeking experience. Doubts about the care process were related to profit-making motivations (private hospitals and doctors); sincerity and commitment (government hospital and their doctors); and about the knowledge and skills of doctors (rare and occasional).

Some interactions and group discussions raised concerns about the deteriorating standards of medical professionals. Community members thought that the number of private medical colleges was increasing, and they were producing doctors without adequate knowledge and skills required for medical practice. *Krish's uncle commented that the newer generation of doctors were not clear about treatment decisions. Further, he added that if a doctor was getting his education/degree by paying money then he was less likely to be a good doctor. In his analysis, one of the important reasons for not taking responsibility for the patients was that the current doctors were professionally less sound than the earlier ones. Due to the lack of sufficient exposure/experience in private medical colleges, they were less likely to be confident in taking*

responsibility for patients. He invoked examples that drew parallels with the education sector- of students who understood little going on to become teachers. Several boys had passed their examinations by cheating and had now become teachers when they were incapable of doing even simple calculations.

Doubting the knowledge and skill of the doctor that they had consulted (they had chosen that doctor) in their treatment process was rare. They had numerous experiences of the treatment not working and persistence or occasional progression of the disease despite treatment, but that still did not make them question the overall knowledge and skill of the doctor. The assumption, in such instances, was that the treatment did not work for the patient despite the efforts of the doctor. They were accepting of the possibility that the doctor, despite his effort, may not be able to arrive at an accurate diagnosis and treat the ailment. In such cases, the treatment provider could be changed, but people still did not question the doctor's skill and knowledge levels in any serious manner.

However, there were instances in the care seeking journey when both patients and their relatives became suspicious of the doctor's financial motivations.

Common illnesses and OPD consultation.

The most common interaction between doctors and community members was for treatment of common ailments in the OPD People were mostly doubtful of the extensive prescriptions given at this stage and phase of care seeking. *While showing the drugs Radhabai had taken from private practitioners; the family observed that the doctors prescribed too many medicines. Dr. Gudewar's prescription was available, and it contained almost 7 medicines to be taken orally every day. The son said and believed that doctors were also unsure about the condition because of which they prescribed combinations of different medicines in the hope that either would work. However, the costs of these medicines had to be borne by patients. Doctors were also known to have tie-ups with the medical stores whereby they earned some proportion from the total sale of the medicines from these drug stores. Radhabai's son had said that this tendency of the doctors to prescribe multiple medicines raised doubts about the doctor and about the usefulness of the medicines prescribed. He also added that there is little choice but to go to the private practitioners*

Common IPD

Community members also suspected that unnecessary surgeries like appendectomy and caesarean section (the most doubted procedures) were being prescribed to patients. Hysterectomies had also gotten added to that list. The commonly held belief was that a large proportion of caesarean sections were unnecessary and done by doctors to extract more money. Nayan and his family firmly believed that the first caesarean section done on Sulekha was unnecessary and could have been avoided if she had been taken to a government hospital, in particular, the government medical college hospital.

For her first delivery, Anita was taken to Dr. Bawalekar's private nursing home where she was admitted for a day, but post-examination, was ***told that she would need 2-3 days for delivery. On hearing this, her family in a bid to avoid hospitalisation costs, decided to take her back home. Later the doctor told them that she was likely to deliver by 8.00 pm. Dual and contradictory opinions from the same doctor made Anita and her family suspect that the doctor was planning for a caesarean section operation.*** *To avoid this, she was taken back home and later gave normal birth to a baby at CHC, Loha.*

According to community members, hospitalisation in private hospitals often left them feeling forced into unnecessary surgeries, procedures, investigations, and prescribed medicines and consumables excessively. Occasionally they had also experienced suspicious and immoral practices around the circulation of these medicines and consumables. *While narrating his experience with the private hospital, Asaya's relative said that his father had hemiplegia three years earlier and was taken to a private hospital owned by Dr. RajAdhav, a neurosurgeon. His father had developed aphasia and hemiparesis. The* ***doctor explained the risks involved with the operation and advised a medical line of treatment. The patient was admitted for fifteen days, during which they spent more than two lakh rupees on the treatment. There was little improvement in his father's condition, and so when the son enquired about the chances of recovery and the degree of possible recovery, the doctor refused to give any prognosis or assurance of any kind. He said that they would just give treatment without any assurance and .asked them to wait and watch if the treatment worked or not. His father was admitted to the ICU of the hospital, where no one was allowed to visit. Frustrated with the lack of recovery despite spending so much money on medicines, he one day entered the ICU and reached his***

father's bed, only to notice that the medicines he was buying daily were not there. It speculated that the medicines were either used for some other patient or were sold back to the medical store. He was very disappointed and fought with the doctor, who began by denying his charges and later passing the blame on to the paramedic, saying it could have been a mistake on the latter's part. *After consulting one of his doctor friends and exhausting all his resources in treatment, he took his father home, where he died after five days. He survived for five days after coming out of the ICU. The respondent was very disappointed and felt cheated by this experience at the private hospital because not only had there been no improvement at all, his father's condition had in fact worsened, despite spending more than two lakhs. He also expressed his sadness at not even being allowed to stay with his father in the hospital and the medicines bought at such expense not even having been used for him. He said that there were some other similar cases that he was aware of where the patient had not improved despite spending large sums of money.*

Referral and IPD

The practice of receiving commissions and kickbacks in referral for diagnostic services, surgical treatments and hospitalisation care was known to the community. Referral advice thus also shaped their experience of seeking care and their opinions about a particular care provider. *Dr. Shende, after assessing her snake bite site, discussed with them in detail the seriousness of her condition and prognosis, along with expenditures for different treatment options. He advised them to go immediately to Nanded and visit the doctor he had suggested. He also advised that if they did not have the money just then, they could go the following day, cautioning them not to delay****. (this raises a question was it a scare tactic? It could have been a genuine concern too with given condition of her feet.) He told them to call him on his mobile when they reached the doctor at Nanded that he had suggested they approach.*** *His advice of getting operated on at Nanded and follow up by getting the dressing at his hospital at the cost of INR 25,000 did not make them comfortable. It was not advice that suited them.* ***Further, his insistence that they call him on his mobile after reaching the private hospital made them more doubtful of his intentions. Madhukar was aware of the practice of getting cuts and commissions for referrals. The overall experience reeked of insincerity, right from the examination, through the speculations about the type of snake and the financially motivated advice of an expensive set***

of unnecessary operations. It was contrary to all their expectations and their faith in this well-known doctor.

Delayed referrals translate into the progression of the disease, delayed recovery and prolonged suffering for patients. However, delayed referrals mean a longer period of hospitalisation for the treating doctor and hospital, leading to more revenue. Some patients reported that they had been kept in the hospital for unnecessarily long durations. Delayed discharge from treatment or referrals for further treatment by doctors were seen as immoral and unethical practices. ***After having experience of taking treatment from the Government Medical College, Nanded, Government Medical College and KEM hospital in Mumbai (the best hospital in the entire state) Shambhu was agitated with the knowledge that when doctors at the apex hospital at Mumbai could not operate and offer cure for the ailment he had, why was he promised and advised an operation at Aksha hospital to begin with? They had kept him waiting for 3 days, before sending him out without any surgery. What capability and experience did the doctors at Aksha hospital have in operating on patients with an ailment like his- quadriplegia with a fracture at C3.4, 5 vertebrae?*** *He indicated that the period of hospitalisation at Aksha hospital was unnecessary and was advised only to extract money. He still wondered whether his condition would have been different had he gotten proper advice and prompt and necessary treatment.*

7.1.12 Summary

Table 7.1 Experiences of Affordability and Cost of Care as Relevant for Quality in Healthcare

Desirable aspects of experience and expectation from health services	Un-desirable aspects of experience and expectation from health services
<u>System structure of health services</u> • Expected these services to be available free or in a manner that would not incur much expenses	• Prohibitive cost of the operation made them take decision of living with suffering. • Nanded added further to the health care expenditure due to higher indirect cost. • **It is not possible to complete the whole procedures in one day** • ***They had to incur the indirect cost for traveling and food for the attendants***

	of the patient • They felt exploited specifically when cost of care was huge- if no desired results or adequate improvement • Lack of alternatives force people to explore the available care options despite knowing that it would mean a catastrophe for the family. • ***He had to sell off a part of his land to meet the expenses of this treatment*** • This expensive care forced on him by insensitive and irresponsible government. hospitals pushed him in to severe poverty. His sad experience of impoverishment is clearly due to denial of care from government. hospital. • Prices of medical care are out of reach for many people. • Sometimes cost of care are so prohibitive that patients have to live in suffering. • he was worried about painful journey ahead of repaying the huge debt. • ***Dr. Shende might be a great doctor and a specialist for treating snake bites (as he is famous in that area,) but he surely is not a doctor for and of the poor people.*** • ***'if somebody is going to seek care at that hospital then he/she has to be ready to sell off their homes and land'.*** • The commission and kickbacks in referral for diagnostic services, surgical treatments and hospitalization care are known among the community. Therefore, referral advice also shaped their experience of seeking care • Delayed discharge from treatment or referrals for further treatment were seen as immoral and unethical practice by doctors.
<u>Medical/ clinical care components</u> • Health care services effective in delivering the intended result and • ***Treatment reduces the total duration***	• This expensive care forced on him by insensitive and irresponsible government. hospitals pushed him in to severe poverty. His sad experience of impoverishment is clearly due to denial

of illness. • ***It also cuts down much of the indirect costs*** *as it reduces total cost on traveling for repeated visits trying out multiple medicines, thus cutting down other losses (the wages lost due to illness, absentee from work).*	of care from government hospital. • *Multiple medicines raise doubts about the doctor and about the usefulness of the medicines prescribed. He further added that there is no other choice but to go to these private practitioners.* • Unnecessary surgeries, procedures, investigations, excessive prescriptions of medicines and consumables incur additional and unnecessary expenditure.
	<u>Institutional features –process</u> • There were occasional experiences of suspicious and immoral practice around circulation of these medicines and consumables. • Doubtful/suspicious practices in health are adding to cost of care was definitely a concern of quality
• concerns of the direct and indirect cost of care were constantly articulated by most of the respondents. These concerns shaped their care seeking journey • and the way they evaluate the outcomes c care process as well as their experience w entire journey of care seeking • Economizing expenditure on treatment and getting relief from suffering were being balanced in their care seeking journey.	• **For minor and less serious condition one cannot afford to spend the whole day at the district town**.

7.2 Perception of quality: Comparison of Quality in Government and Private Sectors

Narratives of the care-seeking had constant references, explicit or implicit, to 'what if an alternative option was chosen/ available'. Every decision in the care-seeking journey is arrived at after repeated evaluation and consideration of different options. Respondents and community members retrospectively assessed and introspected on their care-seeking journeys, where they evaluated for themselves different possibilities and alternate options in care-seeking. This was especially observed more in patients who had undesired outcomes at the end of the care process, i.e. no relief or partial relief from a health problem, delays, further complications, high costs, disability and death. Respondents also evaluated the experience of care seeking by comparing it with those of fellow villagers or other relatives. These comparisons would be on regarding, care received from different health workers of the same institutions; different doctors posted at different points of time at the level of PHC and RH; GPs were compared with doctors at the PHC and RH; comparisons between PHC, RH and DH; specialist and non-specialist doctors; different specialists and private hospitals in the same town as well as from different towns; government medical college and ayurvedic medical college; private medical college and government medical college; traditional healers and qualified doctors among many other factors. The most commonly referred to and important category covering many issues used for comparison was that of the government sector health care institutions and private sector health care institutions.

These comparative categories were part and parcel of their imagination, experience and expectations of- health services. Many of these comparisons were implicitly or explicitly mentioned by the respondents during a discussion on their health-seeking journey. Depending on the nature of the interview and the how forthcoming the respondent was, some probing was done about the comparative assessments of the health seeking journeys in private and public sector healthcare institutions. This comparison revealed strengths and weaknesses of the care provided in both these sectors and helped elicit their perceptions of quality in health care.

Many comparisons pertained to isolated instances or a few health service components. These comparisons were based on their experience as patients, sometimes as family members who accompanied as attendants, and many a time also based on the experiences of their friends, relatives and neighbours. Some comparisons across government and private sector health services were based on their experience of seeking care at multiple levels from both government

and private health services. In some cases, the care sought was for different illnesses at different points in time, whereas for others, this comparison was based on the care-seeking journey for the same illness through a succession of levels in health service delivery system. Some of these comparisons were of value for understanding how people think about 'quality' in health care.

72.1 Spectrum and range of treatment and care services

Tanaji, the 30-year-old son of Mayabai who was attending to her during her hospitalization, said that the government hospital could not be compared with the private because the ***government hospitals were much better than any private hospital in Nanded****. While he agreed that the government hospitals were dirty and overcrowded, a sentiment echoing many others', he still considered the government hospital better in comparison to any private hospital in Nanded. he believed that the* ***facilities and services available and provided at the government district hospital could not be matched by any of the private hospital****s. He agreed that the uncleanliness and crowd at the government hospitals were important reasons for a number of people to seek care in private hospitals. However, he further added that the* ***cost of treatment in government hospitals was negligible*** *compared to that in the private hospitals. According to him, no institution in the private sector could rival the government hospital in the availability of a wide range of the* ***diagnostic modalities and treatment facilities under one roof.*** *Most private hospitals provided a very small range of specialized services, through select individual specialties or a combination of a few specialties. However, none of the private hospitals provided the range of specialized services that government hospitals were able to offer. Similarly, government hospitals offered all kinds of n****ecessary investigation facilities in-house****, as compared to private hospitals, that mostly sent patients to other private hospitals or diagnostic centres for some diagnosis or opinion. A very few of the private institutions had the one or two diagnostic modalities needed for the particular specializations that they catered to in their institutions. The respondent also mentioned that* ***the in-house availability of different specialists in a government hospital, made it easier to have opinions and consultations across departments, about related disease conditions of the patient****. The availability of different diagnostic modalities and experts made it easier for the* ***co-existing morbidities to be treated, and complications could be avoided and handled with efficiency if any arose in the course of treatment****. In government hospitals, the institution provided most medicines, whereas in the*

private sector, everything required for patient care, including materials ***like cotton, gauze piece, IV sets, gloves, spirit swabs, syringes, etc.,*** *had to be purchased from outside (from the market). So, the sheer* ***size and number of doctors and different specialists in the government hospital made it an institution where it was possible to provide comprehensive, effective and wholesome care to the patient*** *compared to the private hospitals available in the district town.* Thus, according to Tanaji, in comparative terms, the government medical college and district hospital with its wide range of diagnostic and curative services, available in one institution, were used synchronously to the best advantage of the patient depending on the requirements of illness management. On the other hand, individual private hospitals were usually very speciality-focused hospitals that provided selected and limited services. Even though all speciality services for diagnosis and treatment facilities, were available in the private sector, these were distributed all over the town in various private hospitals, separated not only by distance but also by the fact that they were separate entities, not well connected to each other.

7.2.2 Going beyond cure to care

Non-medical support services such as access to clean linen, food, transport for referral etc. were also of significance to people seeking care, especially hospitalization care. These additional services shaped their experience, convenience and satisfaction with hospital ***services. Based on the experience of two extended stays for hospitalized care in Nanded, Bishan said that government hospitals provide essential non-medical services, which makes it 'care'*** *as against the medical services provided in the private hospital. These n****on-medical services included the provision of linen, clean bed sheets, provision of support manpower, transportation for referral and, most importantly, the provision of food****. Provision of* ***food from the hospital shared and reduced the attendants' burden, and in his opinion took the treatment experience to a different level, specifically for those from far away rural areas****. If the patient was from a* ***poor socio-economic background, the provision of food was a crucial support to the*** *family.* ***Even those who could afford to invest time and energy in arranging food for their hospitalized family member would acknowledge that managing food within dietary constraints, in the midst of all that precarity - managing multiple treatments, in a new context and city with little knowledge of dietary needs of the hospitalized patient could make the treatment experience a***

nightmare. In private hospitals attendants had these additional burdens to shoulder since they did not provide for important services like linen, transportation for referrals and food.

7.2.3 Rationality and appropriate care

In addition to the medical expertise and support services, respondents distinguished between government and private hospitals on grounds of necessity, rationality and appropriateness of the care provided.

While discussing the rationality of treatments offered in government and private hospitals, Bishan and Tanaji said told that there were numerous examples where ***private hospitals had advised or gone on to perform unnecessary caesarean section deliveries for pregnant women****. Like many others in the village both of them thought that the* ***private hospitals undertook unnecessary procedures for investigation or operation or prescribes unnecessary medicines to earn more money****.*

Even among the medical interventions that were necessary, ***private hospitals would only undertake operations and procedures that would fetch them more money for less effort****. They would only do procedures which will have more money and /or less probability of complications. Private* ***hospitals were more likely to choose procedures that yielded immediate results*** (without considering the implications for health and betterment of the patient in the long-term)

The possibility of conservative management of the patient was less in a private hospital. The respondent believed that the attitude was to somehow net the patient and intervene quickly before he or she thought of an alternative. ***Many respondents said that private hospitals were quick to initiate surgeries and other such procedures without even trying a medical and conservative line of treatment, since the former gave them more money****.*

The drawback in the ***government hospital, according to them, was that it was more time-consuming even though, government hospitals, they believed, provided thorough check-ups and complete and comprehensive care****. The* ***chances of getting rational care in government hospitals, were also very much higher, compared to private hospitals****. Recollecting her experience, Mayabai said that Dr. Bawadekar was only interested in operating her for her gallstones. In contrast, the government* ***hospital had provided her with treatment and cures for***

her mouth ulcers and burning pain in (the epigastric region of the) the abdomen. They also diagnosed and treated her heart condition before operating her for the gallbladder removal*. The treatment that they received did not hold any monetary incentives for the providers. Hence* ***they thought of the treatment they received as the needed, rational and comprehensive treatment****.*

Some of the respondents, when asked to compare and evaluate the doctors in government and private hospitals and clinics said that all that they knew was that ***doctors in the private (institutions) examined them properly, talked to them satisfactorily, and gave medicines without delay, which is why they preferred treatment in the private. The doctors generally responded properly even to repeated queries from patients or (attendant) and patients were attended to as well'. One of the members in the group discussion added 'half of the illness gets better if the doctors talk properly****'*.

The malpractices in the private sector, commissions, kickbacks, the practice of taking a cut and unnecessary medical/surgical interventions, were common knowledge among people and they referred rather matter-of-factly to them. Some respondents were doubtful of the treatment they received, questioned its rationality and appropriateness and the motives of the doctors. *While showing the medical records and the drugs Radhabai had bought from private practitioners, she said that the doctors prescribed many medicines. Dr. Gudewar's prescription was available and it contained almost seven medicines to be taken orally daily. The son said and believed that the doctors were also unsure about her condition, so they gave a combination of different medicines hoping that one of them would work. However, it was the patients who had to bear the costs of the medicines. They said that doctors also practiced charging medical stores a cut for prescribing medicines and directing or encouraging patients to the buy from specific stores, earning some proportion of the total sale from the drug stores. Her son said that the doctors' tendency to prescribe many medicines made them doubt him and the usefulness of the medicines they were prescribed. Further, he added that they had little choice but to go to the private practitioners. On being asked whether the doctor at RH Kandhar would have prescribed the same number and quantity of drugs, he said he did think that the doctors in a government hospital would have prescribed fewer medicines.* Medical malpractice and an overzealous approach to providing expensive treatments were their concerns about the private sector while

indifference and apathy were part of the experience of care received from government-run hospitals.

One of the respondents reflecting on his long experience said *that he had accompanied many of his relatives and friends to a g**overnment hospital for serious medical conditions, during medical emergencies, accidents, injuries and for delivery and caesarean sections. Evaluating and comparing that experience with private hospitals, he said that government hospitals offered rational treatment by avoiding unnecessary investigations and treatment. Community members cited many** examples of women who had normal deliveries at the government hospital after the private hospitals they had first approached advised caesarean sections, were given to substantiate the rationality of treatment given at government hospital as against the unnecessary and irrational practices in private hospitals.*

*On being asked about his overall experience with government hospital services, Bishan considered it to be good on the whole despite limitations in the service and, despite the fact that some of their money and ornaments had been stolen. He further said that if anybody sought his opinion on seeking care, he would suggest government hospitals. **When asked about the long time they had to spend to get that care, Bishan replied that if the patient's condition needed time, as was explained to them by the doctors, then there was no point in rushing things unnecessarily. They did not mind waiting because they developed confidence in the doctor's effort, as was seen in his wife's near-complete symptomatic relief from the condition.** The wait had been worthwhile because it ended in complete cure. He added that the **private hospitals were better for minor illnesses where one could get treatment and return home the same day. It was usually impossible to complete all treatment-related procedures and return home the same day if one had sought care at the government district hospital, Nanded.** Hence when needed, the more practical thing to do was to seek **OPD treatment from a specialist, and then from a multispecialty hospital at Nanded**.*

7.2.4 Prompt, timely and convenient services

The convenience and promptness of health care services were of paramount importance to people from Panshevadi village when they went to get treatment at the distant town of Nanded. To avoid overnight stay in the city, they had to manage the diagnostic and treatment related

procedures within a narrow window of time, hemmed in by limited availability of public transportation facilities, and private auto-rickshaws after a certain time.

When asked specifically about the ***infrastructure, amenities and cleanliness at private hospitals influencing their preference while seeking care, community members said that it that cleanliness was not their primary concern, after all theirs would be a temporary stay and hospitals could not be expected to be clean like people's homes.*** *They reaffirmed that they preferred* ***private hospitals as they offered quick care, along with visible effort by the doctor and relief from suffering. Quick relief from symptoms and being cured of the disease were the focus, specifically when they went to seek treatment outside their village since they wanted and had to return home as early as possible.*** *(Some flexibility was available in the day but only till the time transportation facilities were available in the form of buses or auto rickshaws. Even at night, if they received treatment promptly and experienced quick relief, they could return by the same vehicle they hired to get to the hospital.)*

7.2.5 Sincere approach, humane behaviour and responsible attitude

The private hospital appeared to be the first choice for many respondents. In Ranpat's view the ***private hospital doctor attended to patients quickly, examined them, intervened promptly (gave oral or injectable medicines and fluids, took blood samples for investigation). The patient would be under his watch and he would put in some effort to offer the patient relief. He would also inform the patient and attendants of the prognosis. A doctor's sincerity, quick and visible effort to treat the patient and the relief experienced by the patient were what helped in developing confidence in a doctor.*** *According to him, such service was possible only in private hospitals. On the other hand, in government hospitals, doctors were busy. Hence,* ***the doctor was unavailable most of the time and when he did arrive, was invariably late and would neither examine the patient nor talk to the patients or their relatives properly. Treatment would not start immediately; and even when it did, it would rarely be delivered with sincerity and care.*** *Most of the time, most medicines also needed to be bought from outside; hence, it was not as though care given in government hospitals was free.*

*He also commented on the behaviour of the doctors on duty in government hospitals. The d****octors in government institutions would attend to their friends, relatives and acquaintances, and were***

more committed to fulfilling their personal and social obligations while neglecting the patient who craved his attention. If the patient's a relative requested the doctor to see the patient, relieve their pain or anxiety, the latter would rarely respond promptly, delaying visits to the patient while lingering over conversations with friends, relatives or attending to an influential visitor. *Doctors went out for tea or snacks or with friends, visitors or other staff, often making the patient wait in pain and suffering. To Ranpat this was* ***evidence of the doctor's insincerity and lack of earnestness in providing care. To his mind, to make doctors more responsive, if needed, their duty hours should be reduced from eight to six, but once the doctor was on duty, he should be attending to his professional responsibilities sincerely and not causing delays****. He believed that the doctor should be empathetic to the patient's condition, pain and suffering, try to intervene with complete commitment and without any other distractions to, relieve it.*

According to Keshram, the promptness in service provision was the *advantage that* ***private hospitals offered. Waiting lines and queues were small, doctors were not rude, and there was room for a conversation where the patient could inquire about the nature of his or her illness and treatment options for the same. In reality however,*** this room for dialogue might not materialize, even in the private sector that they viewed as more responsive, given the asymmetry of knowledge and power between doctors and patients. Many of the respondents (Arvind and Vithoba) had also pointed to their inability to talk to private specialist doctors also in a manner that helped them have satisfactory answers or a proper understanding of the nature of their illness and its prognosis. At times, even repeated enquiries, did not yield sufficient information about their illness.

7.2.6 Overcrowding, waiting time, delays, unsatisfactory consultations

The government hospitals were underfunded, understaffed and resource-starved and despite their lengthy and bureaucratic institutional processes, and poor work cultures to boot, they had excessive patient loads to deal with. Such conditions of service delivery, could only result in unsatisfactory if not undignified and inhuman care giving to patients. Feelings of being insulted, dehumanized, and neglected were not uncommon in many of the care-seeking experiences in government hospitals, as narrated by respondents. They pointed to these as the precise reasons that pushed them to opt for treatment from the private sector.

Common to nearly all respondents and community members seeking care at government hospitals was the experience of overcrowding. The overwhelming number of patients handled by government hospitals translated into difficulties in getting OPD papers, having to share hospital beds with fellow patients, long waiting times for appointments for necessary diagnostic tests and surgical interventions. On the other hand, doctors in private hospitals could be accessed relatively quickly without similar bureaucratic processes. The decisions for diagnostic tests were taken promptly, tests conducted quickly, and doctors lost little time in initiating treatment interventions. On the other hand, the g***overnment medical college and district hospital at Nanded was avoided because of its inflexible and unsuitable timings, heavy rush and long queues. It was very inconvenient for Vithoba being a clerk in a government office, to manage office timings and treatment at the district hospital navigating the rush, narrow window of time for treatment and the running around from department to department****. However, he also opined that **government hospitals** were where one could expect **the best and correct diagnosis since they** did not work to fulfil their economic interests or profit motives. He also said that his first preference would have been for government hospitals, but for the long queues and rush that proved to be big hurdles that also took a lot of time, forcing him to choose to go to private hospitals.*

To several patients, being able to consult the doctor properly, with sufficient time and having the illness, its prognosis and treatment communicated in understandable terms was of paramount importance. When consultations did not convey adequate information, were too short, or without room to seek clarifications the patient constantly doubted whether the doctor had understood the problem and whether the treatment offered would relieve symptoms. Possibly, some complaints did not get communicated to doctors in a very short consultation. The experience of consultations differed significantly in public and private sector institutions. *Reflecting on their experience with a private clinic, Radhabai's family felt that doctor had prescribed her unnecessary medicines. When asked whether treatment at the government hospital would have done better, she said that the government hospital would have helped relieve her symptoms but would have taken more time than the private hospital. Even though they thought the treatment itself would have resulted in relief in the government hospital, her family members were sceptical about the whole experience in a public sector institution where doctors would arrive late for examining the patient, would not talk properly, and wouldn't give them personalized*

treatment with care. To one of her family members the delay in receiving treatment at government hospitals was due to the overload of patients and partly due to the attitude of doctors, who relegated their duties and did not take responsibility.

Reflecting on his experience with many patients at government hospitals, Vithoba pointed to the callous attitude of government doctors and hospital staff. He said that at lower-level institutions like the sub-centres and PHCs, health workers and doctors were usually unavailable during emergencies. When one went to a higher level like RH Kandhar, the hospital staff and doctors were not sensitive and responsive. He said that they usually were not prompt in attending to the patient. If someone went to call the doctor repeatedly, they'd be met with the usual dialogues like, *Yes, I am coming.*

You are not the only patient that I am attending to.

This is not my duty.

I have many other patients to attend to.

Wait for some time.

We don't have medicines so buy them from outside or take the patient to Nanded etc.

When the doctor eventually arrives, he would not talk politely to the patient or attendants. A thorough examination would not be done in many cases. The frequency of visits of the doctor is less in government hospitals, specifically till RH level institutions. The doctors rarely discussed with the patient and the attendants their common anxieties, questions and concerns about the disease condition, treatment options, and the prognosis and effectiveness of the treatment provided.in their comparison of the government hospitals at Kandhar and district headquarters at Nanded they said that the services provided, including number of times and thoroughness with which the patients might be examined and their treatments monitored, was likely to be much better at the government medical college and district hospital at Nanded.

7.2.7 Choosing /cherry-picking patients

There was constant comparison between private and government hospitals where the former was characterized as being more responsive and communicative in their provision of care. The government institutions lacked any mechanism for grievance redressal and there was little answerability or accountability, especially at RH and hospitals at higher levels. However, some respondents, did point out that responsibility, accountability and answerability, as seen in private hospitals, were applicable only for the patients they had chosen to cater to. Private hospitals were also known to reject patients with certain disease conditions or with complications. *Radhabai's son said that as an auto driver he had taken many patients to private hospitals and seen the latter simply refuse to provide care when the patients were in a serious condition due to a severe accident or otherwise or had developed complications. On the other hand, the government hospital with all its drawbacks did not do so and if the condition was beyond their capacity, they'd examine the patient and provide primary care before referring him or her to an institution at a higher level, making sure they had proper support and after they had provided first-aid or emergency treatment. At higher levels, if the patient was not in a condition that they could manage, at least they would admit him or her and make the effort to provide care, not simply turn the patient away as private hospitals did. Government hospitals did not refuse treatment and care.* He had also observed that. *They would not refuse treatment even when such cases entailed uncertainty about medical histories of the patients; slim chances of survival and the possibilities of recovering costs of treatment and care.* On the contrary *private hospitals refused care to patients whose identities were not known (unconscious patients brought from accident sites, unaccompanied by relatives).T*he *private hospitals only catered to simple, neat, uncomplicated, manageable case with assured profit. In sum,* they chose simple and easily manageable health problems, where taking responsibility posed minimal or less of a challenge and provided care for them.

Another respondent, while discussing the strengths and weaknesses of government and private hospitals, also added that only government hospitals took on medico-legal cases. He said *that* ***private doctors and hospitals exercised the liberty to choose the patient and avoided severely ill, complicated or even medico-legal, post-mortem and accident cases. Given this situation, government hospitals were the only option for a seriously ill patient.***

7.2.8 Affordable health services

Free or economically priced health services from government hospitals was one of the important features that made government health services, valuable to the community, enabling access to necessary services compared to unaffordability or steep price of treatment from the private sector. When asked to compare the private and government hospitals, Keshram was more favourably disposed to the government hospital and said that ***he would still prefer it, firstly on economic grounds- a*** *procedure that would cost him around INR 5000-6000 in the private hospital was provided to him nearly free of cost. at the government hospital. He added that in the* ***private hospitals there was a high probability of unnecessary diagnostic test****s, d****espite which the diagnosis could still go wrong. Apart from operation costs, private hospital doctors prescribed strong and unnecessary medicines. He said that in most cases, doctors had networks with the medical stores from where they got cutbacks. Hence, they prescribed too many, often unnecessary medicines to earn more money. Thus, the chances of being given irrational treatment were high at private hospitals whereas it was at the government hospitals that one had greater chances of getting an accurate diagnosis and rational treatment.*** *This was another cause for him choosing government hospitals and evaluating them as better than the private. He said that private hospitals tended to extract as much money as possible from the patient in every possible way since they functioned to fulfil their profit motive, which could egg them to any extent to earn more money.*

Though the services provided by government hospitals were free, patients had to incur some opportunity costs to avail them. It was told by many of the respondents while explaining their preference for private sector clinics and hospitals from the same town over government hospitals ***that considering the cost-benefit analysis ,they choose the private hospital because it holds chances for both lower direct (treatment costs) and opportunity costs (wages, additional travel seeking treatment from higher level institutions) in cases where it accepts and chooses to respond to illness promptly with high end medicines because of which the duration of illness itself is shorter especially for minor illnesses needing OPD consultations. .***

7.2.9 Privacy and personalized care

Private clinics and hospitals with a limited number of patients offered the possibility of getting due attention from doctors. The respondents usually pointed to this aspect of care in the private sector when contrasting it with their experience in government hospitals. A few respondents also mentioned that private hospitals did offer the possibility of treatment with some privacy, personalized attention and care. Health emergencies, conditions like a precious pregnancy or first pregnancy (specifically in ***economically well-off families) demanded immediate response and more attention and hence, private hospitals were preferred for such conditions, given that they offered personalized services****.*

7.2.10 Summary

The overall image of the care at government hospitals was very poor as far as community members of Panshevadi were concerned. The brand image of the services provided at a government hospital is low, specifically with regard to dimensions of service provisioning including timeliness of services, caring attitude, convenience, flexibility, manner of interaction and communication with the patients and their relatives. In addition, very poor cleanliness and hygiene, poorly maintained infrastructure and amenities, overcrowding, long queues, and substandard medicines of suspicious origin and effectiveness are also contributors. However, the image of the government hospitals fares better with respect technical dimensions of the accuracy of diagnosis and provision of appropriate and rational treatment.

They also stand tall in the eyes of the public with regard to the dimension of cost of care. On the other hand, the respondents thought that the private hospitals served them by providing accessible and convenient services in a timely and time-bound manner. The services provided were humanely, with politeness and in careful and dignified manner. Patients and attendants felt more confident in discussing health problems and their prognosis with private healthcare providers since they were paying for the services.

Table 7.2 Perceptions of Quality from Their Comparison of Government and Private Sector Health Services

Desirable aspects of experience and expectation from health services	Un-desirable aspects of experience and expectation from health services
System structure of health services • ***Cost of treatment in government. hospital is negligible*** • ***Number of diagnostic modalities and treatment facilities available in government. hospital as one institute cannot be matched by any of the private hospitals***. • ***In-house availability of different specialist*** • ***From private hospitals one can get treatment and return back home the same day***. • *Government hospital caters to accident cases where there is no relative of the patient, or unknown patients where there is uncertainty about patients' medical history, the chances of survival and of the financial recovery of costs after giving the treatment.* • ***Government hospital is the only option where seriously ill patient is also admitted and treated.*** • ***Reduces the total duration of illness. It also cuts down much of the other(indirect) costs as it reduces total cost on traveling doing repeated visits trying out different sets of medicines,*** • ***Lower opportunity costs especially for minor illnesses needing OPD consultations.***	**System structure of health services** • ***It is usually not possible to complete the treatment procedure and go back home from Nanded in government. district hospital*** • Private hospitals were usually very specialty focused hospitals providing selected and limited services from that hospital • Commissions, kickbacks, cut practice and unnecessary medical/surgical interventions- malpractices • medical malpractice and overzealous approach • Absent mechanism for grievance redressal. The answerability and accountability is lose and amorphous • Choosing disease conditions for management, private hospitals exercise discretion in choosing patients too • *Private hospitals only cater to simple, neat, uncomplicated, and manageable and profit making cases* • ***Exercise the liberty of choosing the patient*** • Cost of care especially high cost of care
Institutional features - inputs • Extent of ***facilities and services available and provided*** • *Availability of different diagnostic modalities and experts* • *Medicines are available and are provided from within* • ***Co-existing morbidities are treated and complication can be avoided*** • *Sheer* ***size and number of doctors and***	• ***Materials like cotton, gauze piece, IV sets, gloves, spirit swabs, syringes etc. also have to be bought from the market in the private hospital*** • *Where as in private everything that is required for patient care has to be purchased from outside (market).* • ***Private hospital in the city did not have provision for some of these important services like linen,***

different specialist in the government hospital makes it an institution where it is possible to provide very comprehensive, effective and wholesome care to the patient • *Provision of n**on-medical services like provision of linen, clean bed sheet, provision of support manpower, transportation for referral and the provision of food from the hospital***	***transportation for referrals and food.***
<u>Institutional features - process</u> • *Sheer **size and number of doctors and different specialist in the government. hospital makes it an institution where it is possible to provide very comprehensive, effective and wholesome care to the patient*** • ***Private hospitals are quick to act in*** • The convenience and promptness • ***Provided services immediately. Waiting line and queues are small.*** • *Health services with some privacy and along with personalized care and attention* • Timeliness of services, caring attitude, inconvenience, flexibility, manner of interaction and talking to the patient and the relatives, • Accessible and convenient services in a time bound manner, • Treatment in humane manner with sincerity, care, dignity.	• *Dirty and overcrowded government. hospitals* • ***Time consuming*** • Overcrowding • Overwhelming number of patients • difficult to get OPD papers, hospital bed had to share with fellow patients, there were long waiting times for getting appointments for necessary diagnostic tests and surgical interventions • ***Unsuitable timings of the district hospital along with heavy rush and long queues*** • ***Heavy rush and department to department or door to door running involved in the district hospital*** • Bureaucratic institutional process and absence of relatively quick decision making. • Absent mechanism for grievance redressal. The answerability and accountability is lose and amorphous • Overcrowding and long queues, substandard and very poor cleanliness and hygiene, ill maintained infrastructure and amenities, substandard medicines of suspicious origin and effectiveness
<u>Medical/ clinical care components</u> • ***Thorough check up and complete and comprehensive care**. The **chances of getting rational care*** • ***Treatment they received was the 'needed, rational' and comprehensive treatment**.*	• No relief from health problem, partial relief, delays, further complications of health problem, excessive costs, disability and death. • ***Un-necessary procedure for investigation, or operation or prescribe un-necessary medicine***

• ***Rational treatment by avoiding unnecessary investigations and treatment.*** • ***Quick care, along with some visible efforts put in by the doctor and relief from the suffering. Quick relief from the symptoms and cure of the disease was seen as important specifically when they go to seek treatment outside their village as they want to and have to return back to their homes as early as possible*** • The decisions on needed diagnostic test were done readily and tests were done quickly and interventions were also made as early as possible. • ***Possibility of getting best and correct diagnosis*** • ***Correct diagnosis of the condition and rational treatment*** • ***Reduces the total duration of illness. It also cuts down much of the other(indirect) costs as it reduces total cost on traveling doing repeated visits trying out different sets of medicines.*** • ***Lower opportunity costs especially for minor illnesses needing OPD consultations.*** • Doing correct diagnosis and giving appropriate and rational treatment	• ***private hospital will do only those operation and procedure which will fetch them more money without putting in more effort and care****. They won't do procedures which will have less money or some complications are involved* • ***Doing any procedure and operation without trying out medical and conservative line of treatment*** • Commissions, kickbacks, cut practice and unnecessary medical/surgical interventions- malpractices • Thorough examination is not done in many cases. Frequency of visits of the doctor is less • Common anxieties, questions and concerns of the patient and the attendants about the disease condition, • The treatment options available, and the prognosis and the effectiveness of the treatment provided are not discussed with patient or the attendants. • ***Probability of doing un-necessary diagnostic test, chances of getting irrational treatment***
<u>Attributes and features of provider</u> • ***Doctors in private examines them properly, talks to them satisfactorily, and gives medicines without delay*** • ***Each time queries are answered satisfactorily and patients are attended too.*** • ***'Half of the illness gets better if the doctors talk satisfactorily'****.* • ***Satisfactorily explained to them by the doctors, then there is no point in rushing the things un-necessary. They did not mind in waiting because they developed confidence about the doctor's effort, as seen from her near***	• Medical malpractice and overzealous approach • Indifference and apathy • ***Doctor not available immediately.*** • ***Doctor will come late, he does not see patient properly, he won't talk to the patient or the relatives properly. Treatment won't be started immediately, when started it will be without sincerity and caring attitude.*** • ***insincerity and lack of earnestness*** • Inability to talk in satisfactory manner to understand the nature of illness and prognosis of their disease condition;

complete symptomatic relief from the condition. • ***Doctor will attend to the patient quickly, he will examine the patient, he will start intervening in the form of some activities (like giving medicines, taking blood samples, giving injectable medicines or fluids) directed at the patient. He will keep a vigil on the patient and put in some efforts to relieve the patient of the condition for which the patient is taken there. He will relieve the suffering and tell us the prognosis of the condition*** • ***Sincerity, quick and visible efforts put in to treat the patient along with relief from the suffering*** • ***Doctors are not rude and*** • ***there is scope for having a conversation where patient can inquire about the nature of illness and treatment options.*** • Given satisfactory information about their illness. • They could seek answers from the treating doctor, to many of their questions and concerns about illness as well as manner of care provided. They felt that there was scope for some negotiation and dialogue on some aspects in that care process	• Feelings of being insulted, dehumanized, neglected, uncared were not uncommon • Hospital staff and doctors are not sensitive and responsive. • Usually don't come to attend the patient soon • Won't talk in polite manner
• ***it's just a temporary stay and hospital cannot be as clean as homes*** • ***Duty hours of the doctor should be reduced from 8 hours to 6 hours but when doctor is on his duty he should attend to his professional responsibilities sincerely without any delay***.	

7.3 Discrimination and other Sociological dimensions in the experience of seeking care

The experience of feeling under-confident with their rural lifestyles, unkempt looks and uneducated or undereducated status was a common feeling with the respondents' and community members' experience of seeking care, especially when they went to the district town. This was

true also when they had to interact with doctors and nurses and other technical staff in both government and private facilities. Some said that big buildings with several wings and departments, and highly educated, confident doctors and nurses left them feeling intimidated or overawed. Often, they felt hesitant and reluctant to seek help or ask questions of the doctors and nurses. Their gender, caste, economic and educational status, and age affected their confidence in navigating space and people at these health care institutions. Given the social distance and attendant power dynamics between the professionals and people from the village community it was challenging and risky for the latter to bridge this gap and feel at ease while interacting with the professionals and using those institutions. Health care professionals especially those doctors who attempted to put them at ease, made them feel confident enough to share their problems and were sincere in listening to their problems were remembered as good doctors by them.

However, at institutions at the lower levels of the health care system (closer to their village and in the block town that they visited regularly) people probably felt the social distance lesser and there was some confidence in their ability to manage seeking care. Women, poor, uneducated and elderly had higher chances of still feeling under-confident in interacting with the GPs and medical officers at the RH. They expressed the fact that they could not communicate their problem to the doctor entirely, or feared disturbing the doctor when seeking clarifications. They were too shy and sometimes scared to talk to the doctors.

The dynamics changed significantly in their village PHC which they were familiar with, and been to regularly and where the doctors with their transferable jobs were often relatively new. At the PHC in their village people felt relatively more confident in talking to the doctor during consultation and at times felt easy enough to demand services from doctors and other health workers.

Their confidence in seeking and demanding care was higher at the lower level of the health system, especially at the PHC. Those who were confident and assertive got the health care they demanded. There were others who did not get the required services despite their need, request or demand, and felt discriminated against at the PHC. Feeling discriminated against is relational, where seeing or knowing of others getting services, or getting better attention affects the perception of treatment meted out to one. The higher levels institutions were, possibly, too

overwhelming to even feel discriminated against and there was no one from their context or known to them, for them even to compare against. Experiences of preferential treatment given to some patients were not uncommon at the government hospitals. Many respondents reported that the possibility of getting services or getting better and timely services was higher if they knew someone in the hospital staff. It was widely known that relatives and friends of the hospital staff would get preferential treatment. Hence secondary and tertiary health care institutions like RH or medical college and district hospital were used less frequently by them as compared to the GPs, private hospitals and the PHC.

7.3.1 Discrimination

Feeling discriminated against was one of the important factors shaping people's evaluation of the health care provider/institution and determining its use in future. Respondents spoke about the experiences of feeling discriminated against because of their caste, gender, class and political affiliation in the village.

The village was a small place where most people knew each other as did the medical officer at the PHC who also knew the socio-economic status of the visiting patients as well. In their assessment of services provided to them, people observe and compare their own experience with that of others and analyse the difference in terms of caste, class, gender, political affiliation, power, nuisance value and confidence. Familiarity with other people who were getting a different treatment made the comparison possible and easy at the PHC rather than the district hospital. *Reflecting on her experience Krish's mother said that in the PHC* ***patients who were forceful, powerful, threatening or had potential nuisance value would get all the medicines, proper treatment and polite behaviour from the PHC staff.*** *(This was applicable at the RH to some extent but at the RH and above, those players were different, the power dynamics operated differently. With larger staff numbers the staff too had some security and power.) She then added that many times* ***she has taken her kids and even sought consultation for severe diarrhoea, but she or her kids were never given syrups or IV drugs, whereas other male members or patients accompanied by male members even if they were relatively less severely ill, who were talking or walking properly, were given the IV saline****.*

She reported that on multiple occasions she was sent away without any treatment saying that there was less blood in their body. On asking the probable reason for this experience, she strongly felt that it was the absence of a male family member with her and her child. She said that her husband was working as a truck driver and was away from home most of the time. So, she alone had to take care of her children and take them to hospital whenever they were ill. ***Overtime she had been observing that patients accompanied by an adult male family member got proper treatment- enough medicines, tablets, injections and I.V. saline. If a male family member was present, then the hospital staff also talked to them properly. She said that the absence of adult male member during the treatment experience gave her different kind of treatment experience. Presence of male member act as pressure factor for the hospital staff and they behave in a responsible manner with the patient. With this experience over time she also does not feel like using the PHC and had stopped using it.***

Many respondents from the 'Mang' community conveyed that they often felt discriminated against at the PHC. They were used to discrimination in the village and in the PHC while the powerful members of upper caste communities in the village received preferential treatment. They reported they were made to wait for longer, and it was quite often that their fellow villagers, upper castes, jumped queues at the PHC. They felt that they were often not given sufficient time for consultation by the doctor as compared to their upper caste patients, and the functionaries including doctors had a casual attitude towards them, making them wait, being dismissive of their demands. Many of them reported that they don't receive adequate physical examination especially with stethoscope and measuring blood pressure as compared to upper caste patients. They were aware of their position in the power hierarchy and the relative lack of power to change things at the level of PHC. PHC medical officer was well aware of the power dynamics in the village and members of the Mang community felt that he was not doing his job with neutrality.

Villagers well connected in the existing power structure in district's political ecosystem were given preferential treatment. Others felt discriminated on many occasions with this kind of treatment given to them in PHC. *Ranpat who was having high grade fever with severe abdominal pain was taken to the PHC with the help of his family members. He was made to wait in the PHC while doctor was talking to a politically influential person from the village. Doctor while*

chitchatting with the politically powerful person was also fulfilling his demands. The doctor gave him routine injection for diabetes or some other illness. Ranpat waited and was attended to after the doctor had addressed the influential person first. Ranpat then added that doctors and health workers in the government institutions attended to people depending on their face and appearance (value and ability to influence). He was pointing out that the care provided at the government institution did not depend on the seriousness of illness but on the familiarity with the doctor, the class and background of the patient that translated into the patient's ability to influence through power and political connections. H*e said that* ***at the PHC people connected with the local political leadership- of the gram panchayat, panchayat samiti or in the Zilla Parishad got privileged services i.e. those patients would be treated in a polite manner, be offered a seat, examined thoroughly, using a stethoscope, BP apparatus, would be given IV fluids even for the smallest of complaints like simple cough, kept under observation in the PHC for some time, and referred to higher centres with proper explanations about where and how to go. Sometimes they were sent with proper referral letters from the doctors at the PHC.*** *However, a****n ordinary person, with serious illness, without political affiliations would be turned away with a few tablets, or would be asked to go to Kandhar or Nanded***. Radhabi and her family had a similar experience. *They said* ***that there was*** *differential and discriminatory behaviour by the doctor in providing treatment. Doctors were providing personalized services with IV drugs and IV fluids, considered better forms of treatment yielding quick results, to politically influential families in the village.*

While reflecting on the reason for discriminatory behaviour on the doctor's part, community members ***said that the doctor from outside was neither related to any of the patients nor did he benefit financially by providing early care to the politically influential person. In the given power structure, political interventions in the form of transfers and misuse of power by political leadership were probably threatening for the doctor. According to them if the doctor did not oblige the politically influential, he might be endangering himself both professionally and physically.*** *Apart from routine examples of transfers* ***they pointed to the example of one of the finest and most popular doctors at RH Kandhar, who was beaten up by the politically influential people (the doctor was a dalit doctor and politician upper caste- though in popular memory it was not discussed as a case of caste-related violence, that the doctor was soft target needs to be recognized).*** *However, Nayan insisted that despite these constraints, doctors could*

and should learn to creatively handle these political interferences and social responsibilities without compromising professional responsibilities. The doctor should politely sensitize and educate his friends, visitors- specifically politically influential visitors about the seriousness and necessity of his professional responsibilities.

Krish's uncle while commenting on the discriminatory behaviour of the medical officer in the PHC stated that *doctors usually addressed the* ***concerns of those who were politically influential and could potentially have an impact on their existing ways of functioning. Most of the times, health functionaries themselves had limitations and lapses in their performance, which put them in a position where they were forced to maintain good relations to keep those with influence on their side. Hence, services provided by health functionaries reflected the power dynamics of the village.*** *He was of the opinion that all the people in the village should get the available services in accordance with the illness they were suffering from and without any kind of discrimination.* ***He suggested that PHC staff should not take part, imbibe or practice the power politics of village*** *and emphasized on ensuring* ***equal access and delivery of available services to all without any discrimination.***

Fighting discrimination

The PHC was the location where experiences of felt discrimination on the basis of caste, gender, class and political affiliation were articulated by many respondents, but given that the institution was located in their own village, they were confident of getting some of this discrimination redressed. Some community members had attempted to point out this discriminatory behaviour to PHC functionaries to stop it. Some of them had even fought against the discriminatory behaviour of doctor and had a verbal fight and heated arguments with him. Sadanand *gave the example of* ***health workers from PHC who had been selective in their home visits****, going to see on the politically connected and economically well off people.* ***Their prejudicial behaviour had invited hostility and lack of trust from the community****. It had resulted in tension and heated conflict between him and one of the* ***doctors, when the doctor refused a home visit to attend to one of his relatives who was feeling breathlessness and couldn't be brought to the PHC. Sadanand then objected to the discretionary and discriminatory home visits and threatened the PHC staff and doctor of dire consequences if they made any such selective home visits in the future. After this threat, the doctor after consultations with other PHC staff, got ready to visit***

the patient. However, by that time they had made alternative arrangements for taking the patient to Kandhar. The doctor visited and treated the patient and the Kandhar trip was averted. This also showed that ***a stiff opposition and the willingness to fight by members of the community were effective in getting the PHC doctor and staff, to respond, albeit under specific circumstances.***

Citing another example, ***he said that once he took a patient, his relative, to the PHC and the doctor prescribed them a medicine and asked them to buy the same from the market, saying that the medicine was out of stock. A little after he questioned them on the inventory inquiring when and how much of the stock had arrived, and how much of it was distributed and how; some bottles of the medicine were brought from the stock and given to him. He then went on to say that people like him who fought and questioned the functionaries at the PHC got better services but those who lacked this ability did not get proper care from the staff. In conclusion he reiterated that doctors and the staff at the PHC judged people based on their appearances, gauged their capacity to influence politically or otherwise and treated them accordingly***.

Most people noticed prejudicial behaviours, while some of them fight against it, others sought alternatives. This unfairness however maligned doctors and resulted in lack of respect for doctors and other health professionals. Their experience had led the people to conclude that doctors and health professionals worked only if there was some kind of pressure on them or a threat issued. So everybody was trying to pressurize and threaten health workers in their own ways. ***Dinu narrated his personal experience where he had threatened a health worker and subsequently got better treatment whenever he went for to the PHC in the village. He added that it was only the better off and the influential from the village get better treatment at PHC and rest or the poor would have to go to private clinics at Kandhar to get dependable and effective treatment. He also was of the opinion that the new trend of pressure tactics should stop immediately. According to him it was possible that change in behaviour was needed at both ends- people as well as professionals.***

It was important to make sense of who could put up a fight against the discrimination? Even though political affiliation was one of the important basis for the discrimination practiced, it was those who were not affiliated with the politically powerful in the village who had managed to put

up some fight against discriminatory behaviour of the doctor. There were few such stories but all of them were from upper caste men, some of who were not rich but were not poor either, e.g. middle level farmers. Gender and caste were other two bases for feeling discriminated but women and people from formerly untouchable castes could not fight against discrimination. Hence even the ability to question PHC staff and doctors and fight their discriminatory practices rooted in local social and political hierarchies needed one to have some kind of social and cultural capital, in Panshevadi it was caste.

Alternatives to discriminatory treatment

The power of socio economic status and political affiliations to get doctors in both the public and private sectors to be responsive was reinforced time and again. Nayan while discussing his daughter-in –law's experience of hospitalization in a private hospital, *said that the hospital gave them prompt attention, and they were very appreciative of this aspect of the service provisioning. He further added that* ***he had pressurized (threatened them mildly with consequences) the doctors using his political links with a famous MLA and mass leader from the region, demanding better and appropriate services especially after the new born baby's hospitalization***. ***He had insisted on better services that he was willing to pay for, and had threatened them with unpleasant consequences if the infant developed any further complications or suffered any inconvenience***. *I****n the latter part of the interview he submitted that the kind of money he had to spend and the connections he could summon would not have been possible for others***. The poor and the Dalits would not have these resources and neither have the confidence or ability to demand.

Discriminatory and undignified ways of treating patients was an important reason for people avoiding government health facilities and preferring private hospitals. *Krish's uncle* ***expressed readiness to pay in the private sector for getting the same treatment (investigations and medicines) as in a government hospital where he would not have received the same services in a satisfactory, respectful or dignified manner.*** *If the same set of medicines were being used in both the private and government hospital for a given condition, h****e preferred paying and using private services since he would be treated with respect and would have satisfaction. In government institutions, these free services though available but often accompanied by humiliating experience.*** Dignity emerged as a very important aspect of the patients' experiences

with health services and it influenced their choice of care provider. Many a time dignity was chosen over cost of care. While, paramount importance was given to cure, dignified recovery was preferred over free treatment provided in a humiliating or undignified manner. The concerns of dignity and self-respect during care-seeking were articulated more often by respondents of upper caste Maratha community than the lower caste Mang community members.

7.3.2 Social expectations about health care

Deteriorating government- run health services are very well-known and a widely acknowledged fact that has led to its poor image in the eyes of the public. Over time, government-run health services have acquired an image of being poor services for poor people. Government health services were perceived as those which were used only by poor people incapable of paying for better care-the lower castes, Muslims and women. The choice of health care providers, especially in terms of public or private, was also a statement of one's social status. *On asking the reasons underlying higher utilization of private health care and underutilization of government run health institutions, Radhabi and her family said that the convenience offered by the private institutions in terms of timings, quick treatment, and relief from the illness were some of the important reasons for it. Concerns of social status also led people to avoid using government run services. There was social pressure to utilize private hospital services to show that one cared for their near and dear ones. This was based on popular belief and the brand image of government-run services as poor, inhuman and substandard with respect to many dimensions. The only advantage of government-run services was that they were cheaper. Hence going to a private hospital was a way for people to show that they cared for their dear ones and did not mind spending money on them.*

Arvind said that the treatment he got for his psoriasis in the private (sector) from two skin specialists was not of any use to him and had cost him a lot. When asked why he did not use the government Hospital, the researcher realized that the reason was his readiness to spend money was also tied to the prestige involved in obtaining treatment from the private hospital and the indirect social pressure to take treatment from private hospitals, as a means of establishing caring for one's own when they were ill.

7.3.3 Social relatedness / connectedness

Social distance between patients and health care providers affects the nature of interaction and care giving and care seeking experiences. The larger the distance, there is more indifference towards each other's needs and requirements. The lesser the social distance the greater the likelihood of knowing each other's needs, requirements, strengths, weaknesses and understanding each other. The shared social and environmental realities will make understanding each other easier. Krish's uncle said *earlier* ***doctors used to stay in the PHC, whereas over time the proportion of doctors staying in the village was going down. The availability of doctors who resided in the village made a significant difference in their accessibility, behaviour and approach. Dr. Padam, during his previous posting in the PHC few years preceding the interview stayed with his family for many years as the PHC medical officer. Evident from several interviews was the fact that he had earned significant trust and goodwill among most villagers.*** *His stay in the village while posted at PHC and the relationship with the villagers made him* ***take responsibility for the patient while treating. The willingness to be responsible for the patient's wellbeing gave confidence to the patient and relatives and encouraged mutual trust. While this study was being conducted, most doctors were not staying in the village and were relatively more hands-off in their engagement with the patient, so causing the trust and confidence the patients and their relatives had in the doctor to be eroded.***

Familiarity with the social context of patients made the process of care easier for both the doctor and patient. *On asking the doctor what he liked the most Vithoba More said that being from relatively better off class, he got better treatment from most doctors he visited. He had visited several doctors in Kandhar and many specialists in Nanded for treating his son's arthritis, his wife's facial palsy and had accompanied other relatives for treatment too. However, he went on to add that doctors like Dr. Sugadekar (medical officer from RH Kandhar) who came from a humble background were the more liked ones as they were more likely to be sensitive in their behaviour and in a better position to understand the circumstances of the patients and their suffering. Doctors from humble socio-economic backgrounds were likely to understand the realities of the patients while treating, advising and dealing with patients and their families.*

7.3.4 Gender and hospitalization care

Gender played an important role in deciding when and where treatment would be sought. Government health institutions especially lower-level institutions were mainly used by women. The PHC and CHC had acquired an image of being institutions for health care mainly of women and children.

Gender shaped and affected the hospitalization experience of patients and their families. Institutional arrangements of services and their processes affect the hospitalization experience for women patients or as attendants. Women attending to a male patient have to live with and suffer because of gender insensitive institutional arrangements. *Sonawane was admitted to medical college hospital for TB, his wife was his sole attendant during that hospitalization. Reflecting on their experience of that time her suggestion included that of ensuring installing drinking water facilities in accessible places. She had to walk from one corner of the hospital to another and felt unsafe to walk to a corner of the hospital to bring water especially late evening and at night.*

Women patients in government hospitals often had to be segregated from male attendant due to gender segregated wards and rules and regulations around female wards. These institutional arrangements causing inconvenience, to male attendants potentially contributed to delayed, inadequate or no care to women patients for illnesses requiring hospitalization care from government hospital. *Tanaji while sharing a month-long hospitalization experience that his mother had been told that at least two attendants were constantly needed with the patient- one with the patient and another for running around, need for carrying the patient to different departments for investigations and opinions of various experts whenever needed or to bring medicines and material prescribed, from outside. Hospital required at least one of the relatives with the patient in case of medical emergency or for getting consent or to explain the progress and future line of treatment. Hospital did not have any provision for the stay or to accommodate the attendants of the patient. In some cases, one attendant was allowed to stay with the patient for the initial few days. Most of the time male attendants were needed for running around and making necessary purchases, or to make decisions about the future course of action in treatment. However, the male attendant would become a problem for female patient in female ward. Most of the times attendants had to spend their nights either in some corridor or corner of the hospital*

or outside the hospital on the footpath right in front of the hospital. This institutional arrangement of requiring female attendants for female patients in the female ward, made it a difficult task for family to mobilize a female attendant to be there at the district town. Care seeking for women especially from rural areas was cumbersome and at times impossible for some families, unless it was a life-threatening emergency situation. The need for more attendants could be cut down significantly if the hospital had sufficient support staff and institutional mechanisms that called for fewer attendants. Attendants usually made up for the lack of support staff in the hospital, as well as for deficiencies in the hospital provisions especially for procuring consumables like medicines. Institutional design- infrastructure and institutional mechanisms should be structured and organized keeping in mind their status as a referral hospital serving patients from distant rural areas with no support in the town.

7.3.5 Summary

Table 7.3 Discrimination and Social Dimensions Relevant for Quality in Health Care

Desirable aspects of experience and expectation from health services	Un-desirable aspects of experience and expectation from health services
System structure of health services • At lower levels of institutions (close to their village and at regularly visited block town) the probability of feeling social distance was less and there was some confidence in their ability to manage seeking health care • Probability of people feeling confident and seeking care and demanding care was higher at the lower level of health system, especially at PHC.	
Attributes and features of provider • Doctors who attempted to make them feel at ease and made them feel confident to share their problem and were sincere in listening to their problem are remembered as good doctors by them. • *Doctors coming from humble socio-economic conditions are more likely to understand the contextual realities of the patient while treating, advising and behaving with patient and their family.*	• ***There is** differential and discriminatory behaviour by the doctor in providing treatment. The doctors were providing personalized services with IV drugs and IV fluids, which are considered as better forms of treatment* • ***Doctors and PHC staff judges you from your appearance for your capacity to influence politically or otherwise and treats you accordingly**.* • Discriminatory and undignified ways of treating patient

	• ***Not taking responsibility***
	<u>Institutional features - process</u> • Experiences of preferential treatment given to some patients • Experience of feeling discriminated was articulated by respondents for their caste, gender, class and political affiliation in the village • ***Those patients who are forceful, powerful, threatening or with potential nuisance value will get all the medicines and proper treatment and polite behaviour from the PHC staff.*** • ***Patients who are accompanied by adult male family member were getting proper treatment with enough medicines, tablets and injection and I.V. saline. If male family member is present, then hospital staff talks to them properly.*** • ***She told that absence of adult male member during the treatment experience gave her different kind of treatment experience.*** • 'Mang' community conveyed that they felt discriminated in PHC many times • They were made to wait for longer time as compared to their upper caste villagers. The experience of jumping queue to giving preference to upper caste member in the line • On occasions they felt that they were not given sufficient time for consultation by doctor as compared to their upper caste fellow villagers. Casual attitude in approaching them, examining them and treating them, making them wait and dismissing their demand was often experienced by them. • ***People who have contact with political leadership of gram panchayat, panchayat samiti level or at Zillaparishad level get privileged services i.e. these patient will be treated in a polite manner, will be***

	offered seat, examined thoroughly with stethoscope, BP apparatus, will be given IV fluids even for the smallest complain like simple cough, kept under observation in the PHC for some time, and referred to higher centres by properly explaining where and how to go, some time they are sent with proper referral letters from the doctors at PHC • ***If one does not have affiliations with political leadership then he/she will be turned away with few tablets, or will be told to go to Kandhar or Nanded***. • Institutional arrangements of services and its processes affect the hospitalization experience of women as attendants of male patients as well as of woman patients admitted in female wards with male family member as attendant. • Institutional arrangements causing inconvenience, to men attendants might contribute to delayed, inadequate or no care to women patients for illnesses requiring hospitalization care from government hospital

7.4 Perceptions of quality from the Community's Suggestions for quality improvement

Most suggestions for improving healthcare service provision were based on people's experience as patients and attendants of patient- family members. There were also a few suggestions based on the experience of others and on popular perceptions of health services.

While narrating their experiences of care seeking some respondents stated the problem faced and also suggested what could have easily been done to avoid inconvenience they or others who accompanied them faced. These suggestions were had a problem-solving focus, based on the problem that they had faced and the experience that they had. Yet others had suggestions pertaining to healthcare institutions at different levels and there were those that were more generic in nature, applicable to all levels of health care. Some suggestions were applicable to healthcare personnel, while others pertained to healthcare institutions.

It was observed that most suggestions for improvement of health services were intended for government-run health services. It could be because of the enormity and extent of the problem that they faced in government-run healthcare institutions. The health care seeking, was predominantly from the private sector- from providers and institutions like GPs, nursing homes, or specialist-run hospitals. There were many accounts of problems that they faced and bad experiences in many of their encounters of care-seeking from private hospitals and GPs. The suggestions, however, were not made about solving the problems or improving the health service in the private sector. This was also due to an act of inadvertent omission on the researcher's part, failing specifically to seek suggestions for improving health services in the private sector separately. There was scope to enquire about suggestions for improving health services from the private sector, but this gap was recognized much later during data analysis. The absence of suggestions from people to improve the quality of health services from the private sector despite facing numerous problems could possibly be due to issues of ownership. Government-run healthcare institutions are public institutions where there is a sense of public ownership, enabling people to feel like they had the room to suggest and thinking that there was a possibility that the suggestions may be taken on board. Respondents also demanded and expected that the services improve in the government institutions. Suggestions were based on their care-seeking experience, and those who had used private healthcare institutions also tended to suggest improvements in the government health institutions, based on problems they had anticipated in the government health services that made them go to the private sector. Some of their suggestions stemmed from the expectation that if government services improved, they would like to use them rather than the expensive private services.

Most of the suggestions were based on the respondents' experiences with different levels of healthcare institutions. These suggestions were also the expectations that they had for better experience with the health services in the future. Their desires and expectations were also reflected in their suggestions for quality improvement. Though the care-seeking pertained more to the private sector and tertiary care institutions, the suggestions were with regard to the primary and secondary level institutions like PHC and Rhin the public sector.

7.4.1 Primary Health Care

The PHC in Panshevadi was part of people's daily living and was an institution with which they had a long connection, regular interaction and much familiarity. Long-term experience with this institution also made them understand its expected roles and functions along with the limitations of both the institutions and the health functionaries there.

Most suggestions that the community members and respondents who were former patients offered were with regard to the PHC. The suggestions were primarily for increasing the number of health workers, ensuring round-the-clock availability of doctors and some health functionaries at PHC to provide more curative services for common ailments and a wider spectrum of services. Nayan suggested that PHC in their village should tackle most of the common illnesses so that people did not have to go to institutions at secondary and tertiary levels. He was critical of the PHC's practice of referring even uncomplicated deliveries hospitals in the block town and in Nanded. According to him all the necessary provisions should be made at the PHC so that common ailments and conditions like delivery could be handled at right there.

Kavita suggested upgrading the delivery services at the village level so that most of the deliveries and 'family planning operations' could be conducted in the village. She said that family planning operations were earlier performed at the facility in the village, specifically in village camps. However, the camps and operations were no longer being held at the PHC since the last few years. She expressed the need to conduct such operations at the level of the village and suggested resuming the delivery of these services at the PHC. Though family planning operations were performed free of cost at the CHC or district hospitals, she still preferred that they be done at the level of the village PHC because proximity to their home and family ensured easy access to homemade food for patients and attendants, and family members, relatives, and friends could visit easily. Indirect costs associated with staying and travelling to the town and city could be avoided. She also believed that the likelihood of getting the operation being performed early also increased if the procedure was available at the PHC in their village. The need of, difficult to mobilize female attendant required for female patient during family planning operation is less if the operation is done at PHC/ Decision of the family planning operation can be taken quickly without having to worry about attendant and convenience of male family

members to take them to block or district town. This she believed can help in avoiding unwanted pregnancy due to lack of convenient and accessible services.

The availability of doctors around the clock at PHC was a major demand articulated by most people. The doctor at the PHC was available only for a few hours during the morning working hours and this availability was also unreliable. Keshram's experience with PHC had been a mixed one. He said that the doctors were available only for a few hours on working days, hence if there was a health problem that needed attention outside those few working hours, then people did not have any option but to go to Kandhar. Radhabai's son said that in the lower-level institutions like the PHCs, the health workers and doctors were not available at the time of health emergencies, hence the demand for doctors to be available round the clock. Picking from their past experience with Dr. Padam, one of the previous doctors at the PHC, some respondents felt that the doctor ought to be residing in the village, that made a difference to his accessibility. Dr. Padam had also been living in the village, and some respondents recollected the good social relations that they and other people in the village had with him.

However, mere availability of the doctor did not translate into assured access to necessary services. The doctors and health workers needed the ability and skills to provide the services. The lack of necessary support services like diagnostic tests and medicines needed for treatment could also impede service provision. Nayan shared his experience of taking his granddaughter to the PHC when she had convulsions. He was critical of the doctor at the PHC who according to him was not equipped to investigate and treat the baby, and he could not display that confidence. He did not to alleviate their anxieties about the causes and condition of the baby. A seizure was a serious condition for a baby, according to the family and their belief was only strengthened when the doctor told them to transfer the baby immediately to Kandhar. However, all that the doctor at the PHC had to offer, for what appeared to be a serious condition, was regular syrup! They had expected a different treatment regimen for a condition perceived as one of considerable seriousness. This occurrence led to the realization that the PHC and the doctor were not equipped to handle the condition. He felt that well-trained doctors who could handle such emergencies should be made available at the PHC.

Similar opinions were voiced by different respondents about the capabilities of the doctors at the PHC to handle common ailments. Keshram pointed that even when a doctor was available, he could handle only a limited set of illnesses and conditions, offering symptomatic and temporary relief for a very few conditions. The effectiveness of the treatment was not really predictable- sometimes it worked, and if it did not, he advised them to go to Kandhar. For many conditions, there was no treatment at the PHC, hence the doctors asked them to go to Kandhar. Keshram suggested that the PHC ought to provide definitive treatment and relieve suffering not just for common ailments but for a wide range of health conditions.

Respondents had similar complaints about the medicines that were being dispensed at the PHC. The same set of medicines was being given for all kinds of ailments and most of the time, the medicines were ineffective. On the other hand, the private GPs in Kandhar prescribed new medicines, different ones according to the illness under treatment, another reason why they were using services of GPs. Radhabai and her family said that the medicines at the PHC were substandard, usually the same set, irrespective of the illness Often time they did not even provide symptomatic relief. She said that she was doubtful of the medicines supplied through the government-run facilities; both their contents and effectiveness. She said that they needed illness-appropriate, effective medicines that brought relief at the PHC.

Several respondents including Radhabai and her family also complained of the discriminatory behaviour of the doctor, favouring politically influential families in providing treatment. The latter would be given personalized services with IV drugs and fluids, considered better forms of treatment, bringing quick relief. Nayan and his family members said that the doctor was from outside, neither related to any of the patients nor did he benefit financially by providing early care to the politically influential person but he had to oblige patients from politically influential backgrounds to avoid putting himself in professional danger (transfers) and at risk of physical harm. However, Nayan asserted that despite these circumstances, the doctor could and should learn to creatively handle undue political intervention and the pressure to oblige the socially and politically connected without compromising professional responsibilities. The doctor should politely sensitize and educate his friends and visitors, especially the politically influential, about the seriousness and criticality of his professional responsibilities. Krishna's uncle went on to emphasise that the PHC staff should not participate or be influenced by the power politics in the

village. The doctor should aim at ensure equal access and efficient delivery of the available services to all, without any discrimination.

There were others like Radha's son who also recognised the limitations within which health workers worked at the PHC. He felt that the services provided at thePHC had significant scope for improvement. The services were disorganized, the PHC did not even have its own building thatcausedmany problems in its functioning. Currently, the small building of the old sub-centre and part of the Panchayat bhawan that the PHC was housed in, did not have quarters for medical officers to live in, so, doctors did not stay in the village. The unavailability of doctors round the clock affected access to emergency services. The lack of proper infrastructure affected he nature of services provided, specifically for deliveries. He said that there are discussions at the panchayat level about donating some land for the construction of a separate building for the PHC along with residential quarters for other support staff.

7.4.2 Rural Hospital

The RH was used infrequently and only occasionally by the people of Panshevadi. It was most commonly referred to as a stop-gap measure on their way to the district hospital at Nanded in the event of emergencies. Common emergencies like accidents, injuries, snakebites, OPC poisoning, etc., were given basic treatment at the RH before they were referred to Nanded. Medico-legal cases are also seen at RH Kandhar. People regularly used the RH Kandahar for emergency MCH services and routine obstetric cases referred by PHC. Pregnant women were often taken here for childbirth. The institution had a mixed reputation for conducting normal deliveries but also for referring a sizable number of pregnant women to the DH. Many shared common experiences of referred out patients from RH giving normal birth at DH or in the vehicle, en route to Nanded. The RH also facilitated ambulance service for emergencies, to transport patients to Nanded. The experience while using RH for these emergency services shaped their image of RH and affected their use for routine health care. The use of RH in emergency services was usually followed by the use of DH or private speciality Hospital from Nanded therefore, there was some comparison of hospitalization and emergency services provided through these two institutions providing different levels of care.

Barring its limited role during emergencies and for services related to childbirth, the RH was not an institution routinely used by the people of Panshevadi. Those who had used RH as patients or attendants had unpleasant experiences. Radhabai's son, an auto-rickshaw driver (plying the auto between Panshevadi and Kandhar) had taken many patients to the RH and had seen the experiences they had. He said that when one went to an institution at a higher level like the RH, Kandhar the hospital staff and doctors were not sensitive and responsive. They usually did not attend to the patient immediately, they'd be made to wait, would not talk politely, would not perform a thorough examination. The doctors did not visit the admitted patients frequently. Anxieties, questions, and concerns of the patient and the attendants about the disease, available treatment options, the prognosis and the effectiveness of the treatment provided were not discussed with the patient or attendants. Though they still believed that the services provided, including the examinations and treatment given, were much better at the government medical college and district hospital, the improvement they wished to see, was services that were timely, sensitive, effective and comprehensive. Like many of his fellow villagers he was also of the opinion that they should not have to travel till Nanded, most of the services should be available at the RH Kandhar level, and service should be provided in such a way that most of the patients need not go to Nanded. They felt that the RH Kandhar ought to be the epi-centre, catering to most of their treatment requirements, a role that was being played by the district headquarters at Nanded city for both private and public facilities. He favoured Kandhar for its relative proximity, greater familiarity and lower travelling costs as compared to Nanded. Given that the villagers travelled routinely between Panshevadi and Kandhar, communication with the patient and attendants or sending them things was not difficult unlike Nanded which was quite far away.

However as shown in several accounts, RH Kandhar had inadequate infrastructure and human resources. When asked about their experience at the rural hospital at Kandhar, Vithoba More said that they did not go to RH Kandhar for his wife's treatment but recollected his experience of taking a relative's daughter to RH Kandhar for her delivery. He said that the girl had delivered normally, and that was not very challenging for him as an attendant and there were no complications. Even so he had noticed that the RH at Kandhar could do with a lot of improvement in terms of the availability of expert and supporting manpower. It also lacked well equipped diagnostic and treatment facilities, the existing ones did not have all the necessary instruments and machinery. A shared aspect of the experiences of his friends, relatives,

acquaintances, for over a decade now, was RH Kandhar's failure to address their patient's problem, irrespective of the problem they went there with, and their families finally having to take them to Nanded. The institution had a systemic problem, not related to the patients, the nature of their problems or to the health personnel (doctors have changed during this period). He was of the opinion that a lot of diseases should be handled at Kandhar RH so that people did not have to go to Nanded. The place was familiar, so one did not feel insecure, it was easy to ask for necessary help whenever they needed to, avoid delays and find timely help from the village. Taking treatment at Kandhar would reduce (indirect) costs, most importantly, and reduce much of the hassle and inconvenience. In his opinion Kandhar was a critical location for accessing care and health care services there needed to be improved to fill the gap due to the poor functionality of the RH at Kandhar.

7.4.3 District Hospital

The government medical college attached to the district hospital at Nanded offered UG and PG training and hence, is a tertiary-level medical institution. People faced many difficulties to reach this town and obtain treatment at this hospital. Being a hospitalized patient posed additional challenges that if one were only visiting the OPD. This DH had been responsible for saving many lives and relieved the acute and chronic suffering of many people, through medical and surgical interventions as was recounted by several respondents. It had given a new lease of life to mothers going through difficult labour, respondent shared joyful stories of them welcoming new-borns to their families. There were also some sad experiences of lives lost, lack of relief from pain, and the experience of suffering through institutional and clinical processes while taking treatment at the DH.

The district hospital was generally approached for expert opinion or specialised treatment after patients had been through the experience of treatments from different providers and institutions at primary and secondary levels, that had failed to resolve their health problems. Therefore, this institution was the patients' last resort that they approached for final answers and often with the hope of some improvement and respite for their suffering. When he was asked for suggestions for improvement in the government hospital at Nanded, Bishan started with the district hospital and covered a range of services from the PHC to the district hospital at Nanded. He recollected the conversations with the doctor at the government hospital and at Dr. Bawadekar's private

hospital, where they were discussing the possibility of doing the same operation with machines and instruments rather than open surgery (Judging from the discussion, the machine most likely would have been, a laparoscopic operation set). Bishan also recollected the experience of a woman from the village who had also been advised to go to Aurangabad for surgery with that machine. However, she could not afford to go to Aurangabad for treatment so she was operated upon in Nanded with open surgery. He said that if the machine was something that was needed and important for the district hospital, provisions should be made to get the same. He said that the distance to Nanded was already too long and far for rural patients to travel to seek treatment; they should not have to be sent further away to big cities merely for the lack of necessary instruments or machines in the district hospital. He said that apart from the machine, laparoscopic operation set, other machines that the doctors at the hospital thought necessary for providing care should be made available to them. He said that the patients should not have to go to higher centres from Nanded for the lack of machinery.

Bishan had lived in and around the district hospital for more than a month as an attendant to his wife when she was admitted once for a medical problem and the second time for gall bladder removal. Having seen the hospital closely, he reflected on his experience of living there. According to him the hospital building needed maintenance as several of its structures were in a dilapidated condition, toilets and bathrooms were in very poor condition. Timely maintenance and painting of the hospital with regular cleaning to maintain hygiene would make it more pleasant for the patient who was admitted. The physical amenities had scope for much improvement. While reflecting on their experience at the district hospital, he stressed the need for augmenting necessary manpower in terms of nurses and supporting staff for better delivery of care. He said that all necessary provisions needed for keeping the hospital clean and well-maintained needed to be made. He further added that these suggestions were applicable to both the RH Kandhar and the district hospital.

The district hospital, in particular was used for hospitalization, when the health problem under consideration had become serious and the patient's condition was poor. The district hospital on the contrary was located very far away. Medical college and district hospital was a very big institution, a very intimidating place (especially for these rural folks) with its massive infrastructure, large number of doctors, nurses, and other technical experts and health workers,

and a wide range of services and departments, to add to this there were complex institutional and bureaucratic processes. This background made attendants essential for patients during their hospitalization. Sufficient support of health human resources and appropriate institutional mechanisms would reduce the requirement of attendants with the patient during hospitalization. The intimidating nature of the hospital also affected peoples' abilities to make decisions, one of the important concerns that affected their willingness or the lack of it to opt for free or relatively cheaper services from the government medical college and hospital.

While discussing possibilities for further improvement in healthcare facilities of the hospital Asaya and Madhukar began by highlighting the issue of the inconvenience of attendants. The hospital did not have appropriate arrangements to accommodate attendants and this was something that should be provided for at the district hospital. Every patient has one or two attendants who had to struggle through the institutional processed and deal with unfriendly staff and ill-equipped infrastructure and services at the hospital. The absence of support for attendants coupled with the inconvenience associated with receiving services pushed patients into the private sector, which offered some convenience and amenities, and quick services, reducing the length of treatment and the number of days one had to be hospitalised. If the private services were unaffordable, then the inconvenience that care seeking at the district hospital posed even led people to opt to leave the condition untreated for long durations of time till complications arose. It was important to understand and address why is there was a need for attendants; how the number of attendants required could be cut down on by improving the strength of paramedical workers along with the supporting staff and by cutting down the medicine and supplies needed from outside the hospital. Revisiting and rationalizing the bureaucratic institutional processes in the hospital would also cut down the need for attendants. If government hospitals built trust and faith in the community and improved their brand image, then the number of visitors and attendants would go down as they would be confident of getting appropriate and humane care from the government hospital. Attendants would then be needed primarily for emotional support and consulting through the line of treatment for important decision. These attendants need to be provided with the appropriate facility to stay in as they would not have any support structure in the far-away district headquarters. They also suggested developing some institutional arrangements which could improve and ensure cleanliness of the hospital. Madhukar detested the overcrowding at the hospital, and the people’s habit of chewing tobacco, gutkha, and pan and

spitting in the building and its premised making every corner, window, and door of the hospital dirty, unsightly with spit stains. He emphasised on the need for mechanisms that ensured and enforced cleanliness of the hospital. He also suggested fining those who spit in the hospital, an increase in support staff involved with cleaning and suggested that the staff needed to be organized in an efficient manner.

7.4.4 Ayurvedic Medical College Hospital

Ayurvedic Medical College Hospital was another major institution used and fondly remembered by many villagers. On asking him what needed to be done to further improve the overall treatment process, experience and quality of care provided at the Ayurvedic hospital, Bhagirath replied that if one had to suggest improvement, then that would be in ensuring that the hospital provided all the medicines and other materials needed for. If the hospital itself provided the medicines and other materials without any charge, then it would further reduce the cost of care, and more poor people would be able to access care. He said that for poor people, government hospitals were the best options available for seeking care.

7.4.5 Discussion

The experience of care seeking and the problems that people faced had led them to express major concerns- the desire for relief from symptoms, prompt and appropriate care, humane behaviour by a doctor, and easily accessible services (process-related dimensions), whereas their suggestions for improvement focused on infrastructure, more services, human resources, equipment and medicines (structural/input related dimension). It shows that people can see the underlying linkages between the two. In the absence of input-related factors, a better experience is not possible (at the same time, better availability of structural/input-related factors doesn't necessarily mean a better experience).

Another major concern highlighted and evident at every stage of care seeking affecting their decision was the cost of care. Most of the suggestions revolve around strengthening public health services. None of the respondents, however, made any suggestions for covering the cost of care, rather they suggested investing in public services. (This could possibly be because the question was about suggestions for improving health services and did not specify public or private hospitals such in money interactions. The question was not on suggestions for covering or

reducing cost of care.) This is an interesting question to explore with detailed discussions by keeping quality in health care as the central point. Health insurance is a popular and attractive mechanism of health provisioning and it would be a worthy exercise to explore in detail, perceptions of people on health insurance, now that we have some populations using health services under different insurance mechanisms. Few attempts were made even during this research study to explore their opinions on an insurance mechanism when respondents were forthcoming and interested in an ongoing discussion. However, this was limited to one or two questions to a couple of respondents, and one of the respondents gave his response. Radhabai's family members, when enquired about cost of care mechanism to address it, said that for minor illnesses, they went to private hospitals since they are more convenient. For major diseases, private hospitals were simply not affordable, and government hospitals were the only option available for them. They said that one had to be ready to spend, irrespective of the costs, for that treatment from a private hospital. They further added that private hospitals usually offered temporary treatment and not permanent cures for the disease. Government hospitals usually offered permanent cure. Getting permanent cure from a private hospital, called for huge costs. When asked for comparison between government and private hospitals and their suggestions (keeping costs outside the picture, I asked them to respond to a hypothetical situation- if the person was insured and with a guarantee of the cost of care being paid by the insurance agency). Then after thinking for some time, the auto driver son of Radhabai said that he would rate the government hospital better in treating patients. On being asked the reason, he said that many a times as an auto driver, he had taken patients to private hospitals and observed the hospitals simply refusing treatment and care when patient was in a serious condition or the case was complicated or the patient had a severe accident case. They just turned the patient away from their hospital whereas the government hospital with all its drawbacks did not refuse treatment if the condition was beyond their capacity. Then after examining the patient, and offering first aid, they would refer the patient to a higher level with proper support and after emergency treatment. At higher levels, if the patient was not manageable at least, they admitted the patient, put in the effort and provided care, and did not simply turn the patient away like their private counterparts. Government institutions did not refuse treatment and care. They also catered to accident cases where the patient was unidentified or had no relatives. They would make the effort even when such circumstances meant uncertainty about the patients' medical history, however slim their

chances of survival, and those of financial recovery of costs after treatment. Private hospitals on the other hand only catered to neat, uncomplicated, manageable, and profit-making cases. This narration clearly articulated the value and importance of having government-funded and government-provided health services in their lives.

No one had any idea about the regulation of the private sector, it was a non-issue for them, even though the problems they cited could be dealt with through regulatory processes.

7.4.6 Summary

Table 7.4 Perceptions of Quality Based on Their Suggestions for Improving Health Services

Desirable aspects of experience and expectation from health services	Un-desirable aspects of experience and expectation from health services
System structure of health services • ***PHC in their village should tackle most of the common illness so that people don't have to go to higher centre*** • ***All the necessary provision should be made at PHC so that common illness and condition like delivery can be handled at PHC.*** • *Need to conduct FP operations at the level of village and suggested of starting these service from PHC.* • *For logistic reasons like closeness with family ensures easy access to homemade food* • *the likelihood of getting the operation done early also increases if operation is available close to them* • ***Own building by the PHC*** • ***RH Kandhar should become the epi-centre catering to most of the treatment requirements.*** *(Currently district headquarters serves as this centre where most of the services needed are available in government. as well as private.* • *Traveling cost and time needed is much less as compared to Nanded, so it offers convenience, and familiarity and support mechanism can be mobilized quickly from the village* • ***Availability of expert and supporting manpower.*** • ***Augment and fulfil the lack of diagnostic and treatment facility by providing it with necessary instrument and machineries*** • ***Lot of diseases should be handled at Kandhar RH so***	• ***No quarters for medical officers to live*** • ***Patient should not be sent further away in big cities for the reason of lack of necessary instrument or machine*** • ***Whatever other machines doctors in the hospital think are needed in providing care to the patient should be provided to them. It should be ensured that patient does not have to go to higher centres from Nanded for the reason of lack of machinery***.

that people do not have to go to Nanded.	
Institutional features - input • Availability of doctor round the clock at PHC • *doctor should reside in the village* • *Well trained doctors who can handle such emergencies be made available at PHC* • *making different medicines available to cater to different ailments and disease types-they should be effective in giving relief* • *Improvement in the physical amenities in the hospital* • *Augmenting the necessary manpower in terms of nurses and supporting staff* • ***Some arrangements for convenience of attendants should be made available at district hospital.*** • ***Medicines and other material is provided from the hospital itself without any charge***	• ***Institutional processes and unfriendly and ill-equipped infrastructure and services at hospital.*** • Number of attendants required can be cut down significantly by improving the paramedical worker strength along with number of supporting staff and by cutting down the medicine and supplies needed from outside the hospital. Revisiting and rationalizing the bureaucratic institutional processes
Institutional features - process • ***Hospital clean and well maintained*** • Sufficient support health human resources and appropriate institutional mechanisms would reduce the requirement of attendants with patient during hospitalization. • ***institutional arrangements which can improve and ensure the cleanliness of the hospital.*** • ***Monetary fine to those who spit in the hospital. He further told that number of supporting staff involved with cleaning had to be increased further***	• Revisiting and rationalizing the bureaucratic institutional processes so that the number attendants required can be cut down
Medical/ clinical care components • *PHC should provide some definitive treatment and relieve suffering for common illnesses and wide range of health conditions.*	
• To get relief from symptoms, prompt and appropriate care, • humane behaviour by doctor, • easily accessible services (process related dimensions) where as their suggestion for improvement are for more infrastructure, more services, more human resources, more instruments equipments and medicines (structural/input related dimension). It shows people can see the underlying linkages between the two.	• Attributes and features of provider • *Pointed out the callous attitude of government. doctors and hospital staff and expected doctor to be sensitive.* • ***Doctor can and should learn to creatively handle these political interventions and social responsibilities without compromising professional responsibilities.*** • ***PHC staff should not take***

	part, imbibe and practice the power politics of village. Provision of equal access and delivery of available services to all without any discrimination

Chapter 8 Summary and Discussion

Introduction

Examination and analysis of the care-seeking journey of people helped in understanding how people think of 'quality' in health care. The care-seeking journey varied depending on the nature of illness, available health services, and people's preferences, along with the affordability of care. Different phases of the care seeking journey with its important aspects as experienced by people along with their reflections on that journey have been discussed in the previous chapters. When people's responses about their expectation and experience, in each of these phases, offered insights that cast light on their expectations from health professionals and health services. This reflective narrative and insights have been used to identify different dimensions of quality as perceived by members of Mang and Maratha communities from Panshevadi village in Nanded district.

This average village from the backward region of Marathwada in Maharashtra had a population that had presented with different types of communicable and non-communicable diseases, along with incidents of accidents and injuries. This relatively high burden of morbidity meant high requirement for healthcare services, but interactions with community members in Panshevadi also showed that a substantial chunk of the healthcare needs in the community went unmet. Government health services were deplorable, especially at the PHC and RH levels. On the other hand, the private sector, with broad penetration of services, was unregulated. The district town had a medical college hospital each of both modern medicine and ayurveda, and a relatively large pool of different specialists and super-specialists.

This context made the experience of care-seeking very complex, and people had not only several experiences to share, but also a long list of expectations from health services. The reflective narratives of their care seeking journey, as studied, articulated people's experiences and expectations with the health services, with some aspects as desirable and others as undesirable to them. It is essential to understand these identified factors as relevant for understanding 'quality' in healthcare in a manner that will enable existing mechanisms and frameworks of quality assessment and improvement. Community perceptions enrich our understanding of quality in healthcare and need to be factored into mechanisms of formal quality assessment. People's

expectations about healthcare quality, if used to define quality and shape quality assessment and improvement initiatives, would lead to health care services that are more relevant to the community's felt needs.

Implications of the findings of community perceptions from the study have been divided into four groups to make them relevant to existing quality assessment and improvement frameworks and mechanisms. This classification is based on the levels of health services system related functions and who would be stakeholders in improving the quality of those services. The four categories of community perceptions of quality in health included

1. Dimensions of quality amenable to health policy and governance actions
2. Dimensions of quality operating at the level of healthcare institution
3. Attributes and features of healthcare providers as dimensions of quality
4. Dimensions of quality operating at the level of the delivery of medical care

These categories are not mutually exclusive or exist in a watertight classification; it is more indicative. The nature of healthcare services was such that there were overlaps, e.g., general practitioners' clinics, single speciality hospitals run by a doctor, or single-medical officer PHCs are challenging to divide into institutions or providers. It is difficult to separate the features of providers from their medical practice. In addition, some of the experiences of people and factors identified as relevant for quality were applicable to two or more of these categories, e.g., rational medical practice is a component of the doctor's medical practice, and it could be a function of standard treatment guidelines decided by the institution or by health policy. This context led to a repetition of some perceptions of quality as they were relevant under different categories. This repetition could not be avoided and has been retained purposefully as quality improvement mechanisms have to be multi-pronged, operating at different levels with each level and stakeholder participating.

These four categories of perceptions of quality are discussed below.

8.1 Dimensions of quality amenable to health policy and governance actions/Dimension of quality at the level of healthcare system structure and organization

8.1.1 Health system policies and practices

Free health services from government-run health institutions were among the crucial strengths of the government system as identified by the people from the village. The members of the Mang community and poor from the Maratha community were both very appreciative of free services offered through government-run health institutions and emphasised their importance. To them the free services provided were the only hope during illness.

Free services, especially from the district-level hospital, particularly for advanced medical care requiring long hospital admissions or surgical interventions, etc., were highlighted by most as an essential strength of services provided through government hospitals.

While many respondents highlighted user fees and payment for some consumables deficient in government hospitals, and many of them also conveyed that the relative cost of treatment is negligible compared to private hospitals. The cost differences for seeking care at the district town level were high, significantly impacting their ability to seek care and also had profound implications for the continuity of treatment and for other aspects of their family and life.

Consultation fees, hospitalization costs, fees for services, and consumables were described as very high and unaffordable in private hospitals, by many. Other expenses like travel, food, etc., for patients and attendants, added further burden on total costs. For some, especially for several of the Mang community members, these costs were beyond reach, leaving no option but the government hospital or foregoing care and living with suffering.

Experiences of indebtedness or impoverishment due to the cost of care were seen as poor markers of the health service system. Considering costs of care, opinions like 'the specialist might be a great doctor, but he surely is not a doctor for the poor' were expressed.

People had felt exploited when the cost of care was high, especially if the treatment didn't culminate in the desired result or if the improvement in their condition was inadequate. These higher costs of care at private hospitals, including the higher costs of medical consumables like medicines, were repeatedly pointed out as a matter of concern. Commissions, kickbacks, cut

practice, unnecessary medical/surgical interventions, and medical malpractices among healthcare providers were common knowledge among community members. The community members had no possible models to aspire or refer to for cost regulation of the private sector. Therefore, it was beyond their imagination and they did not articulate a need to regulate prices of medicines and private hospitals.

The unavailability of services or experts, with very few experts or services even in the private sector, created a situation of lack of alternatives. The lack of other options forced people to use available care, despite knowing that it would be catastrophic for the family. Therefore, the availability of multiple service providers, meant more options at the district and block town level and was seen as desirable by community members.

Some respondents pointed out the lack of accountability and mechanisms for grievance redressal as an essential concern. This concern applied to both government and private hospitals. People felt that there was little answerability in government hospitals due to ambiguity in lines of accountability. Given the number of doctors and shifts in their duties, it was often unclear who was accountable and responsible for the patient. They considered payment for services and control over it was one way to address grievances in a private hospital, though it was not very effective in their experience.

However, for minor and routine illnesses, the dynamics around the cost of care were different as experienced by the people, more so for the Maratha community members who could afford some care. In terms of total cost, including opportunity cost and indirect costs- receiving care from private clinics of general practitioners (GPs) at the block town was the most pragmatic option, and this was reflected in their care-seeking experiences and the opinions about them.

Thus the cost of care was an important consideration in evaluating the experience of seeking care from different healthcare institutions. It played an important role in one of the critical suggestions that emerged from the community- that the block town should become the epi-centre for health care- catering to most treatment requirements of the people of the village. Currently, it is the district headquarters that serves as this centre where most of the services needed are available in both the government and private sectors. If more specialists are available at the block town, especially at the CHC/RH, then it increases convenience, improves access, and reduces the

cost of care. Hence, making the block-level CHC/RH a functional level providing comprehensive care for most of their illnesses emerged as substantial demand.

When seeking care at institutions functioning at different levels, especially in the government sector, many respondents pointed out that there needed to be more coordination among institutions; referring and referral institutions shared little dialogue and even contradicted each other. Therefore, as a district healthcare system, there was a need for smooth coordination so that the institutions appeared as one system, making for an easier, care-seeking experience with continuity, that reduced suffering and saved time and money.

The lack of coordination was not just among different levels of institution but was observed among two institutions of same level. There was no coordination in the activities at two government medical colleges in the city, one of modern medicine and the other of ayurveda, situated just 2-3 Km apart. The lack of coordination was also an issue within an institution and spanned different specialisations, categories of health care personnel in the same institution. Institutions and practitioners of different systems of medicine along with practitioners of the public and private sectors also needed coordination in the interest of health of a patient. The lack of coordination with professional like physiotherapist during treatment had lead poor health outcome. Non-use of these therapeutic services was due to a lack of availability of sufficient numbers therapeutic professionals or systemic non-recognition of the value of such professions. It was observed that many respondents did not use these professionals despite having illnesses that required their service. Many respondents who used their services had been very late in approaching them vis-à-vis their journey of recovery from their health problems. They had not been informed of the relevance of para-clinical and therapeutic services and had eventually approached them at the suggestion of a relative or friend. This lack of coordination among institutions and different types of professionals affected people's health and their experience of seeking care.

The experience of seeking care at the district level at both government and private hospitals highlighted the plight of attendants accompanying the patients. The need for attendants and the lack of support facilities for attendants was a critical impediment in seeking care and especially for women and elderly patients. Attendants had to sleep either in the corridor, verandahs or

outside the hospital on the roadside or pavements, food arrangements were a similar challenge. Regular food was unavailable in and around the hospital, it was mostly snacks. The food in the hotels at the district town was expensive. Arrangements to meet even basic needs like bathrooms and toilets for attendants were absent. Respondents wished that at least the government hospitals would make arrangements that met the basic needs of attendants, for them to have a convenient and sustainable stay. The need for so many attendants and reliance on them would reduce considerably if the number of paramedical workers and support staff were increased, and most medicines and supplies were made available at the hospital rather than them having to be purchased from the market.

8.1.2 Location and distribution of health institutions

The nearest healthcare facility is usually accessed in case of accidents and emergency health situations. Physical distance and proximity was an important factor shaping the use and experience of health service in case of a health emergency. Distance was a substantial determinant even for routine healthcare needs.

The convenience of seeking care, lower travel costs, and less time required for treatment were essential considerations for illnesses requiring OPD care. The convenience of follow-up visits was also better when healthcare facilities were located at a shorter distance. Shorter travelling distances and time allowed the ease of procuring food from home and arranging attendants. In addition, the logistical convenience of seeking care from a shorter distance also meant that the health care facility was at a familiar place and they had support networks that could help mobilize help quickly from their village. People preferred to travel to the block town, 15 kms away, it was well connected to the village and the provision of comprehensive services was at Kandhar was considered ideal.

The unavailability of speciality services (except obstetrics and gynaecology) at block town meant a lack of options for a large number of health problems, pushing people to the district town that was a about seventy kilometres away, making services inaccessible, the inconvenience adding further cost. At this distance the inflexible timings of the district government hospital made accessing care at a subsidised cost even harder hence, people preferred private speciality

hospitals where they could be assured of getting done with consultations and investigations in a day unlike in the government hospital.

Despite their distance and inconvenience, people still imagined seeking care from the district town or district hospital and dared to do so. However, trying go beyond this level was impossible for most of them, from the Mang and poor Maratha communities. Community members felt that patients should not be sent further away to big cities merely because district level institutions were under-equipped, lacking necessary machinery and equipment or specialist doctors.

The probability of people feeling confident and seeking care and demanding care was higher at the lower health system level, close to their village and block towns, especially the PHC. Therefore, confidence in navigating healthcare institutions for seeking care was inversely proportional to the distance of that healthcare facility from the village.

8.1.3 Health institution dimensions

Community members felt that the inadequate infrastructure in the PHC was one of the aspects that interfered with the functioning of the PHC. It needed to be remedied by providing the PHC with a better maintained and constructed building.

They suggested that having the prescribed two medical officers at PHC was necessary for better healthcare services, instead of the one that was posted at the PHC at the time of this study. The absence of resident doctors impacted the availability of emergency health services forcing people to travel outside, rendering emergency services and expert opinion costly. Community members suggested that residential quarters needed to be provided for medical officers at the PHC This would also increase the availability of routine OPD care which was otherwise restricted to very narrow windows of time, and dependent on the presence of the doctor who lived away from the village.

Realizing the shortage of doctors, nurses, and other support staff, it was suggested to increase the necessary number of doctors, nurses, and support staff. It was conveyed that adequate human resources in health system were essential to ensure humane behaviour and responsible conduct from a doctor and other healthcare provider.

Besides the numbers of doctors and health workers additionally their attitudes were also seen as important. A higher proportion of doctors and health workers with *manuski* were seen as essential for providing quality health services.

The deficiencies were not just at the level of human resources but also in other material resources needed for providing health services. Augmenting and fulfilling the lack of diagnostic and treatment services by providing institutions with necessary instruments and machinery were important for providing quality healthcare.

8.1.4 Package of Services provided -Features and diversity

People's experience shapes the image of a healthcare institution in society over time. To some extent, this image reflects the quality of services offered. This image also shapes the possibility of usage and experiences of services used by the people. Health centres and hospitals are social institutions that the society can rely on in times of suffering. If there is societal ownership or attachment with the institution, it reflects that it serves some social function by providing healthcare services. People from Panshevadi, do not see the PHC as a reliable or dependable source of treatment since the doctor is not available round the clock. In addition to the unreliability of doctors, very limited services are offered by the PHC. To make the PHC a trustworthy institution, it needs to tackle a range of common illnesses so that people don't have to go to higher centres. Therefore, several respondents suggested that necessary provisions should be made at the PHC, so that common illnesses and conditions like delivery are addressed there. Women, especially pregnant women, conveyed that the PHC is a dependable institution but only for ANC check-ups. Women would also like to see it providing FP surgery services at the village level.

RH at the block town was not a significant part of their healthcare utilization pattern except for a few emergency conditions like snake bite, childbirth, etc. However, the respondents wanted the RH and Kandhar town to become a place where most of their healthcare needs get addressed since as it is the most convenient location in terms of distance and helps them avoid a lot of expenditure and effort needed for transportation and other logistical requirements.

Multi-speciality services under one roof of the district and medical college hospital were an important strength of services offered there. The availability of different diagnostic modalities

and experts makes it easier to address co-existing morbidities if there are any, and complications can be avoided and handled with efficiency if any arise during treatment. The availability of a wide range of functional and responsive services in one place in a co-ordinated manner makes a lot of difference, especially for patients with serious health problems. This arrangement in government hospitals also saves patients and their families the struggle to search and select the specialization relevant for their illness and saves the effort of running for consultation and diagnostic testing at different private hospitals. To them comprehensiveness is not limited to having a different specialist opinion and integrating and synchronizing to rationalize treatment from all specialists, but also includes all healthcare-related services from therapeutic professions, nursing, food, emergency transport, etc., to give them a holistic care experience so that patients' interface with the institution is a comfortable one.

On the other hand, private hospitals were usually very speciality-focused hospitals providing selected and limited services from that hospital. Such private hospitals have both advantages and disadvantages for patients depending on their illness requirements. Private hospitals cherry-picked uncomplicated, and service needs with assured profit while refusing care to those who may not be in a position to pay or in cases where the effort far outweighed profit. Private hospitals exercise the discretion to do so. This refusal to treat was seen as a disadvantage of private sector hospitals. On the other hand, government hospitals are the only option where a seriously ill patient may be admitted and treated. An important strength of the government hospital was that it caters to accident cases where the patients may not be accompanied by attendants or relatives, or may be unknown and the situation may be complicated by the uncertainty about the patients' medical history. The chances of survival, and the recovery of treatment costs may be slim in such case. However, government hospitals offer assured care to all patients even in these circumstances, and is an important indicator of functioning and quality of the healthcare system.

In the district town, an institutional arrangement such that one can complete consultation diagnostic testing if needed, get treatment, and return home to their village on the same day was seen as an important requirement, especially for illnesses that required only OPD care, though difficult in the government district hospital and it was more likely possible in private speciality hospitals.

Another factor that was identified as an essential dimension of the quality of healthcare was the care that reduces the total duration of illness. It also cuts down much of the other (indirect) costs as it reduces the cost of travelling, repeated visits, and trying out different sets of medicines. The probability of such care was seen as higher in private hospitals. However, while a treatment cutting down on the duration of illness and giving quick relief was appreciated, there was also a caution against overzealous approaches and medical malpractice in private hospitals.

Timely discharge from hospitals and appropriate referral were other important dimensions of quality. Delayed discharge from treatment and unnecessary or delayed referrals for further treatment were seen as immoral and unethical practices on the part of the doctors. The commission and kickbacks in referral for diagnostic services, surgical treatments, and hospitalization care are known among the community. Therefore, referral advice also shaped their experience of seeking care.

Institutional capacities and practices of addressing medico-legal concerns also shaped people's healthcare utilization patterns, especially during accidents and medical emergencies like organophosphate poisoning. It was the government hospitals like the RH and DH that were handling most such cases.

8.1.5 Non-medical services offered

The provisions of non-medical services like linen, clean bed sheets, support manpower, and transport for referrals are critical issues in patient care.

Crucial among non-medical services is the provision of hospital food, significantly shaping the overall healthcare experience and its quality. Poor, elderly, and members of the Mang community remembered the experience of seeking care from tertiary levels like district hospitals and medical college hospitals as memorable for the food it offered, making it possible for them to continue taking free in-patient care for the prescribed duration.

8.2 Dimensions of quality operating at the level of healthcare Institution

8.2.1 Institutional inputs

Infrastructure

The need for adequate infrastructure to provide clinical and diagnostic services in a health centre or hospital was underscored, especially at institutions providing care at primary and secondary levels like the PHC and block levels. Poorly designed, infrastructure and organization of services unmindful of patients' needs, posed additional challenges while seeking care.

The poor condition of the existing infrastructure at RH and DH was affecting the service utilization experience. The old, poor and ill-maintained infrastructure of government hospital buildings was often dilapidated and toilets and bathrooms in deplorable condition, made the experience of using services unpleasant for many. Some suggested that timely maintenance and painting of the hospital with regular cleaning will make it more pleasant.

Through their care-seeking journey, they highlighted the need for additional support infrastructure and services like drinking water, toilets, washrooms, and bathrooms. They also stressed on the need for facilities to comfortably accommodate attendants at the district hospital.

Inadequate infrastructure and beds to accommodate incoming patients was a common experience for patients from the district hospital. Therefore, upgrading and expanding these were essential for providing quality health services.

Services

At lower levels of care, the lack of services like - diagnostics, emergency medical services, indoor and specialist services, surgical services, etc., was an important problem while seeking care. When available, the service often addressed a limited range of conditions, making them inaccessible for those conditions. Both government and private hospitals at the block town and private hospitals at the district level provided a limited range of services. Patients have to go to different diagnostic centres for the necessary services during hospitalization or OPD consultation.

Round-the-clock availability of doctors and other support services like lab and ambulance service was seen as an advantage, especially for health emergencies, and this advantage was available in government hospitals. On the other hand, private hospitals offered the likelihood of obtaining treatment of choice at a convenient time. Many respondents preferred ayurvedic treatment for chronic health conditions that could not be treated and cured by modern medicine. Therefore, institutions offering ayurvedic medicine were chosen to treat some illnesses, but such institutions were few in the public sector.

The provision of full meals- breakfast, lunch, and dinner, along with tea, milk, and fruits from the government hospital, was appreciated. Provision of food was an excellent thing for the patients, specifically for the poor and for patients from rural areas or all patients who did not have their homes or close relatives in the Nanded city. It saved their money and the inconvenience of mobilizing food according to patients' health requirements.

These non-medical services from government hospitals were what made this experience ‘care’ as against the medical treatment provided in the private hospital. Other non-medical services included the provision of linen, clean bed sheets, support manpower, and transport for referral, and crucial among these is the provision of food from the hospital. Private hospitals in the city did not have provisions for important services like linen, transportation for referrals, and food.

Materials (medicines, instruments, equipment)

Lack of material support for treating the ailment, especially medicines and other consumables, etc., at lower levels like PHC and RH was pointed out as part and parcel of the community’s everyday experience. They have to purchase some medicines prescribed by the doctor from the open market for OPD and IPD care at RH. There was a demand to ensure the availability of medicines and other consumables required from within the hospital free of cost.

At the district hospital, there was a mixed picture - some patients had a positive experience of seeking care with many medicines being provided by the hospital, which saved them a significant amount of money. The coveted IV fluid given freely and adequately during hospitalization was remembered as a positive aspect of the experience of hospitalization in the district government hospital. At the same time, others recalled the experience of purchasing medicine from the open market as undesirable. Care in private hospitals meant that all medicines

and consumables required during hospitalization had to be purchased daily. In addition to medicines, materials like cotton, gauze piece, IV sets, gloves, spirit swabs, syringes, etc., also had to be bought from the market during hospitalization in a private hospital.

The respondents expected the list of available medicines to be extensive so that different types of ailments could be treated. Drugs supplied by the PHC and RH were often suspected of being substandard given people's experience of limited effectiveness. Therefore, the availability of adequate, effective and standard medicines was expected from government-run healthcare institutions. Cutting down on the purchase of medicine and supplies from the open market in the government hospital, would additionally reduce the need for the number of attendants.

Shortage of diagnostic modalities was also an important concern at block towns and at primary and secondary levels in the public and private sectors.

Human resources

The people desired that doctors should reside in their village so that the doctor would be available round-the-clock. It was pointed out that when a doctor was residing in the village, it significantly improved the accessibility, attitude, behaviour and approach of the doctor.

Reflecting on some of the experiences with a doctor at the PHC, they emphasised on the importance of having a competent doctor trained to handle common emergencies. They expected that two doctors (as stipulated) be made available at the PHC and expected that these doctors would be skilful and sincere.

Recognizing the relevance of specialist doctors for many of their healthcare needs, doctors from different specialities were wanted at institutions at the block and district levels. With the experience of seeking care from a district medical college hospital, some respondents, especially those with multiple co-morbidities, realizing the importance of comprehensive care, suggested having teams of healthcare providers with different levels of expertise and professionals. The sheer size and number of doctors and various specialists in the government made it an institution where it was possible to provide comprehensive, effective and restorative care to the patient.

The inadequate strength of healthcare providers was recognized as an important impediment in providing quality healthcare, and the need to augment the necessary manpower in terms of

doctors, nurses, and supporting staff was underscored very often. It was pointed out that fewer health workers, especially support staff, led to poor work culture, which was considered bad for providing quality care. They conveyed the need and advantages of fulfilling the gaps in human resources. Sufficient support staff and appropriate institutional mechanisms would reduce the requirement of attendants with patients during hospitalization.

8.2.2 Institutional processes

Organization of hospital services- overall design of system and policy

Many respondents from both communities were poor especially women struggled to navigate an establishment as large as the medical college hospital, that they found intimidating with its many buildings, bureaucratic procedures and maze of different departments. Internal divisions, referrals, institutional processes, inflexible hours allowing only very short windows of time for consultation and treatment threw them off. It didn't help when in this confusing and overcrowded institution instructions came at them in technical language from unfriendly doctors. They felt alone and even helpless in a town so distant and lacking in the familiar support network of their village. It was evident from multiple interactions and observations that the inconvenience of seeking care has a multiplier effect when patients are women, elderly, or disabled, as they would need more attendants. This context usually results in delayed treatment or no care for such categories of patients, even if services are free. Institutional processes are expected to be flexible, making services more convenient.

Teams of health care providers with different levels of expertise and professionals in district hospitals had made them feel that their illness was being taken care of thoroughly and effectively. These teams of specialists in the government hospital made it an institution that can provide comprehensive, effective care to the patient.

While seeking care from the district hospital, some respondents were impressed with the institutional mechanism of routine supervision, monitoring, and evaluation of work by senior professionals (e.g. MS, Dean, Matron, etc.). They believed such regular supervisory rounds helped in improving work culture and making services better for patients.

Private hospitals were sought for multiple reasons; among these was the ability to negotiate with care providers and demand better or desired services. Community members were also aware that such demands were not usually met; however, payment for services had some possibility of expecting negotiation and demanding better care and accountability. It was pointed out that the lack of clear lines of responsibility in big hospitals, with different sets of healthcare providers and teams of doctors working in shifts made it difficult to demand accountability from the practitioners. The absence of a mechanism for grievance redressal was pointed out as an important lacuna in the district medical college hospital and even in the RH. Even at the level of PHC, the community members couldn't demand accountability from the medical officer- given the wide range of tasks assigned to him, which required him to go out of the PHC village and visit multiple sub-centres and many villages along with attending meetings at block and district health offices.

Administration and administrative procedures – institutional level

Gaining entry as a patient in a government hospital for a person with an illness could be distressing and confusing and is time and resource intensive. Unsuitable timings of the district hospital along with heavy rush and long queues make it very difficult for patients coming from distant rural places. The lack of time and waiting are two aspects of the patient experience in any government institution. Right from the beginning, when people have to get OPD cards made, every successive step in the care-seeking journey involves standing in long queues- for obtaining doctors' signatures, booking appointments and consultations, getting investigations done, obtaining medicines, undergoing procedures etc.

The timings of the hospital and total time required to complete the treatment related procedures become an additional constraint for people coming from far away rural places. One cannot complete the treatment process in one visit. Multiple visits become resource-consuming in terms of time, money, attendants needed, and time of the attendants needed.

The district hospital had its own institutional mechanism of managing services e.g., specific working days for each speciality service, fixed timings, separate appointments for investigation tests after consultations, etc., which make it hard for people travelling from a distant to access even the available services. Added to these restrictions are the difficulties caused by crowds,

queues and long waiting times leading to inordinate delays in completing the treatment. After negotiating all these hurdles, a hasty consultation from a brusque, overworked doctor could be quite dissatisfying and underwhelming. In the case of in-patients, the overcrowding could translate into a shared bed with a fellow patient in the ward and long waiting times for surgical interventions. The services for many were not provided on time, and they did not come with a caring attitude.

Admitted patients in the government hospitals, the DH and RH, experienced insecurities and anxieties whenever there was a change in a doctor's duty. They were not sure about the timings of the next doctor. When the next doctor came, the issue was when the new doctor would attend to the patient. In addition, the concern was that as this doctor was unknown, the patient and the relatives would have to undergo a new cycle of doctor-patient interaction and adjustments. It became difficult for the patients every time a new doctor examined them. This shifting duty created confusion for patients and attendants as to whether the new doctors would know enough about the patient's condition or whether one would have to go over it again. The rapport developed with the earlier doctor was of little use, and having to be in a new relationship with a new doctor undermined the patients' confidence.

Reflecting on the pervasive experience of getting referred out from the PHC and especially from the RH community members were doubtful about referrals to higher centres. They questioned the referrals reading them as a sign of the doctors’ and institution’s unwillingness to take responsibility. Often the referrals were unnecessary or irrational, but also managed without care and sensitivity, leaving the patient to an unqualified person in an unequipped private vehicle.

The poor condition of government hospitals with ill-maintained infrastructure and amenities, poor cleanliness and hygiene, in their opinion, was partly due to the low strength of support staff and partly due to lack of discipline and commitment to work amongst all types the health workers. The poor work culture and attitudes of health workers were often cited as an important feature of government hospitals.

The PHC, with one doctor and the ANM providing health services, was available in the village and formed an important part of their experience of seeking care. Many respondents brought up the experiences of preferential treatment given to some patients at all three government

institutions. They felt discriminated against on the basis of their caste, gender, class, and political affiliation in the village. In their responses, community members objected to the discriminatory behaviour of doctors and other personnel and said that on occasion it had even been insulting.

At the level of the RH and DH, institutional arrangements of services and their processes affect the hospitalization experience of women as attendants of male patients as well as of male attendants of female patients admitted in female wards. Institutional arrangements causing inconvenience to male attendants or the need for female attendants for female patients have implications like delayed, inadequate, or no care to women patients for illnesses requiring hospitalization care from a government hospital. These experiences underscore the need to revisit and rationalize the bureaucratic institutional processes so that the number of attendants required can be cut down on and the stay of attendants can also be made more comfortable.

Though the treatment at government hospitals came with its challenges and inconveniences, the treatment came at minimal costs and often resulted in improvement in the patients' condition. Cost considerations were one of the important factors behind rating the government hospitals as better. Prohibitive costs of the private hospital were both beyond reach for a large segment of the community members and had caused indebtedness and impoverishment for many of those who had used it.

Private hospitals were considered better for their flexible timings, short waiting times and absence of bureaucratic procedures. Private hospitals meant accessible and time-bound services at the patients' convenience. The promptness in services delivered in private speciality hospitals made it possible to complete the whole procedure in one day and return home by public transport. Hospitalization in private hospitals also ensures efficient use of time and resources and gives needed and demanded services immediately. However, in a private hospital all supplies including materials like cotton, gauze piece, IV sets, gloves, spirit swabs, syringes, etc., have to be bought from the market in the private hospital that call for additional expenditure and the presence of at least one attendant.

The PHC on the other hand failed to provide care for more conditions and even though it dispensed free medicines, from their experience people concluded that the medicines were either substandard or were not disease-appropriate. Ensuring the credibility of the medication used at

the PHC and RH is also necessary for building people's confidence in these institutions. Also critical is an effective referral back-up.

Medical care services – the health care provider level

The care process organized in a manner where a patient is getting personalized services was expected by many of the respondents. The pregnant mothers were appreciative that the doctor was present in the hospital at the time of delivery; he had examined her once before delivery. Health services with some privacy and along with personalized care and attention made them feel better during hospitalization. Admitted patients and attendants expect that patient is given frequent attention, care, and treatment. Regular rounds for a check-up by doctors who spoke politely was considered good care. Insincerity, delay or irregularity in the assessment of the patient and required intervention was a grave concern for attendants if they believed the patient was seriously unwell. This was one of the important reasons for attendants and relatives getting agitated and angry with a care provider.

While they expected prompt medical attention and shorter total duration care, i.e., shorter turn-around time, there was a universal expectation that doctors give more time for consultation, listening to patients and thorough examinations. OPD, as well as hospitalization experiences where doctors cared to talk to a patient, spent some time explaining the nature of the illness, and their doubts were remembered fondly. The government ayurvedic medical college hospital was remembered fondly by many respondents since they felt that they received personalized care there because doctors and other hospital staff talked to patients, personally spent time with them, and helped with doing exercises. Interventions like massages, fomentation exercises, showed that health personnel were putting in visible physical efforts in patient care. They felt that they were cared for; somebody was investing time, energy, and skill to get them better.

Some of the experiences from private speciality hospitals for patients were nightmarish despite spending huge amounts of money and seeking care from the best-known super-specialist in the district. Speciality-focused attention to a disease condition with tubular vision of the doctor while managing the patient made them feel sad and angry. One disease condition or some body part being taken care of at the cost of another health problem or body part of a patient was seen as

neglectful healthcare with disregard for the patient's health and wellbeing. They expected comprehensive, safe, effective, and rational health care.

The medical college hospital, on the other hand, was praised for its practice of multiple evaluations of patients by different levels of doctors which they believed contributed to better management of illness. This made diagnosis and treatment of multiple morbidities possible in a comprehensive manner to restore health without having to search for different specialists or wait for one condition to get better so as to treat others.

They believed the presence of multiple doctors in a team from different levels of expertise helps avoid mistakes and increases the likelihood of appropriate care. Such practice was seen as useful in identifying and managing co-existing morbidities as well as for avoiding and managing complications, if any.

They expected wholesome treatment according to the nature of the illness by making use of expertise from diverse specialities and systems, as needed in the treatment process to restore health. Hospitalization in institutions where the doctors' visits were few and irregular made them anxious, especially in private hospitals reliant on consultants. They believed that the changes needed during the course of treatment, would get affected by delays caused by the infrequent visits by the doctors. They expected that treatment should be dynamically responding to evolving health condition of an admitted patient.

Reflecting on taking care of complex disease conditions they felt that to maximize the patient's health benefit, if necessary, it was important for doctors to advice patients to seek or rope in other professionals for intervention, without feeling competitive. Lack of this advice effectively means the patient, while in hospital or treatment from a doctor, is deprived of the expertise and intervention of other professionals.

In addition to having teams of multiple experts, some of the respondents remembered their observations on monitoring mechanisms present in the government hospital, which they believed put checks in place in the treatment process. The monitoring of health professional and patients contributed to building their trust, faith, and good opinion about the government hospital.

However, respondents were doubtful of both doctors' abilities and institutional capacities to manage multiple illnesses or co-morbidities in a comprehensive manner in the existing private speciality hospitals. The same held true for the PHC and RH as well.

Some institutional practices on the use of medicine were also brought up by many community members. In PHC, the prescription of the same set of medicines/ tablets for diverse health conditions made them doubtful about the doctors' as well as the institution's ability and willingness to manage patients' ill health. Whereas private hospitals had the advantage of different and diverse medicines being used in managing patients, there were occasional experiences of suspicious and immoral practices around the circulation of these medicines and consumables. That such practices might be adding to the cost of care was definitely a concern of quality. The respondents expected the institutional process of delivering care and treatment to be provided with some *manuski* (humane approach), responsibility and accountability. They wanted the treatment experience to maintain their dignity.

One of the most important and disturbing elements of the experience of seeking care was that of refusal of care or treatment by the health care provider. Sometimes the refusal of care was partial, where some aspects of care were provided, and others were not. Unnecessary referral to higher centres and the tendency to avoid treatment processes involving effort and hard work by doctors were very hurtful to patients. Many of them talked about being at receiving end of the doctor's tendency to have the patient leave the hospital premises as early as possible irrespective of whether the patient had gotten relief from his symptoms. In a tertiary centre like a medical college hospital, the doctor was known to have sent the patient away because the ailment was not of interest to the health care provider. Experiences where care was refused or people received only partial care were also useful in understanding the quality of care provided.

Upkeep and maintenance of healthcare facility /support services – support staff

The poorly maintained infrastructure and poor hygiene of wards, corridors and toilets and bathrooms led the respondents to view the government hospital as dirty. Overcrowding in these hospitals only aggravated the condition. While dirty and unhygienic hospitals were not liked by anyone, there were differences in the primacy given to cleanliness and maintenance as important factors in decisions or experiences of seeking care. Most people in the Mang community and

some of the poor Maratha community members were accommodative of the problem. They believed hospitals catered to large populations, and were also being dirtied because of the way people used them, despite the effort by the support staff to maintain cleanliness. On the other hand, there were also people who believed that government hospitals were so unclean that some healthy people might get ill there so they preferred seeking treatment from private hospitals over government hospitals which they saw as unbearably smelly, dirty and unhygienic conditions.

Clean and well-maintained hospitals were appreciated by all; therefore, institutional arrangements which could improve and ensure the cleanliness of the hospital were necessary. In those efforts, some suggested monetary fines to those who spit in the hospital. Several respondents suggested increasing the strength of support staff involved with cleaning and maintenance.

8.3 Attributes and features of healthcare providers as dimensions of quality

8.3.1 Qualification and expertise,

In contrast with the popular belief and emphasis on qualification and specialization in human resource standards in quality assessment, people's perceptions of quality revealed that qualification and degrees did not matter much. The postgraduate degree and qualifications were occasionally enquired about and sought by people while seeking care. Most people used specialist services based on information available to them by word of mouth from some known person. The experience of acquaintances with similar illnesses being treated successfully was sufficient for them to choose a health provider. The care provider's qualifications and expertise were enquired about, usually in case of serious illness or when there was no relief from symptoms from a few doctors. They had their own set of doctors who were well-known as good doctors, and some of these doctors were known to them in relation to their ability to manage certain health problems. Expert opinion from a famous doctor gave them the satisfaction that one has made the best possible effort to care for the illness.

8.3.2 Professionals practice attributes

Promptness

Promptness of service delivery, where the doctor acts swiftly and attends to patients without undue delay and starts treatment to relieve suffering, was expected very often and especially so in case of health emergencies. If a doctor is available in the hospital at an odd hour, and ready at the time of an emergency then people appreciated and remembered the doctor. Their absence and the delays they caused was one of the main grouses about the RH. They detested the usual experience of emergency care at the RH, where the government doctors didn't start treatment immediately and rarely attended with careful attitude.

Treatment and care

People expect certain attributes in healthcare providers while receiving care from them. They expected their care provider to be sincere and earnest while taking care of patients and advising treatment. They look for a doctor who listens to their problems, enquires about their health problem, speaks satisfactorily, answers their queries about ill- health, examines them thoroughly, and explains to them about their condition. Health-seeking experiences where they felt that they were cared for and that somebody was investing time, energy and skill to get them better were remembered fondly. Actions in the form of various visible activities (examining patients, giving medicines, taking blood samples, giving injectable medicines or fluids) aimed at treating the patient gave them some confidence. They felt hopeful and confident as something was being done by the doctor, who knew about their illness and the treatment.

They desired that the doctors be polite, and there be room for conversation where a patient could inquire about the nature of illness and treatment options. Someone who puts in sincere effort and provides care by putting in their physical and mental energy is recognized as a good doctor. Healthcare providers who are empathetic to patients and are aware of patients' context while advising are good doctors for them. They assessed their care providers for their skills, efforts, caring attitude and professional integrity. During hospitalization, a doctor who answers the queries of patients and their attendants and attends to the patient whenever requested makes their experience of seeking care less stressful. They also expected that doctors would keep a vigil on

the patient and put in some effort to relieve the suffering and tell them the prognosis of the condition.

Some respondents with chronic disease conditions also expected that if the doctor is aware of the limits of their ability or expertise in dealing with illness, then they should be upfront about care and services they are not in a position to provide and refer the patient to an appropriate provider.

Reluctance, lack of skills and knowledge to treat routine illnesses, and avoidance or refusal of simple treatment interventions from doctors were also some of the negative experiences that people reported from the government sector.

In the care process where healthcare providers don't really make the effort to treat patients, neglecting patients during the treatment process is undesirable behaviour. People complained that government doctors did not start the care and treatment promptly, and when they did initiate treatment, they did not even provide it with care and investment. Often their experience of seeking care made them feel that doctors were in a hurry to get rid of the patients as quickly as possible. The end result of unsatisfactory interactions with doctors during consultations and examinations was the community members having to live with many unanswered queries about their own health.

The tendency of doctors to prescribe many medicines, especially private GPs, raised doubts in their minds about the doctor and about the usefulness of the medicines prescribed. They were suspicious of overzealous prescription and looked down upon medical malpractice. People considered inconsistencies, irrationality or the feeling that the doctor or institution had ulterior motives, ground to discontinue the treatment.

Advice

In addition to treatment, the patient expected appropriate advice from the doctor on various aspects of illness and care. Earnest advice, counselling and information given without greed for monetary gains, with the patient's best interest in mind (as felt by the patient) was expected from a good doctor and was also valued by patients. This advice could be on various aspects of precautions to be taken or dietary restrictions to be practised, how to take medicines, follow-up

visits, exercises to be done etc. In some cases, some of this simple oral and yet crucial advice was not given to patients resulting in further complications in their health problems.

In the case of chronic illnesses with no definitive cure, adequate counselling of patients to help them accept the nature of illness and how to deal and live with chronic disease is very important. Such counselling was not very forthcoming from doctors while many patients desired such counselling to help them make peace with their ill health and stop searching for new doctors for a cure. They expected a doctor who could give proper advice in a satisfactory manner that people could understand. The doctor was expected to advise that they could comprehend and act.

Assurance and responsibility

Assurance, especially of better outcomes, did matter a lot to patients and their relatives and made a lot of difference in the experience of their care-seeking journey. Doctors who took on the responsibility of treating their patients and saw them through, were good doctors to them. The assurance could be provided verbally and sometimes through their actions. Various activities aimed at treating the patient gave them some confidence. They felt hopeful and confident if the doctor demonstrated clear understanding and expertise in his or her knowledge of the illness and treatment. Responsible behaviour on the part of the doctor gave the patient confidence during treatment. Patients expected assurance from the provider and it was their sincere effort to treat the health problem that helped build the patients' confidence.

Some of them avoided going to government hospitals as they had experienced the reluctance of government doctors to assure them of positive outcomes. Government doctors did not take responsibility for the patient and generally found a way out by referring them away to a tertiary care institution. Out of their jurisdiction or at least out of their institution. This, in their opinion, was avoiding taking responsibility of the patient and was not desirable in a doctor.

Referral

They also expected treating doctors, especially from the PHC and RH, to act as bridges between them and experts at higher levels within and across institutions. They remembered the decade-old experience of a doctor from the block town who made the effort of calling and reporting to higher levels, where a patient was referred, about the given patient's condition. This acted as

great support for the people. The referred patients used to get admission without much effort based on earlier discussions with referring doctors.

Relief from symptoms

The ability of the doctor to relieve the suffering of a patient or to improve the condition of the patient was certainly a universally valued trait. There was accommodative forgiveness of other poor experiences if the care process ended with the recovery of the patient from illness. If the patient gets well with the doctor's treatment, then the doctor is considered a good doctor.

Socially sensitive

They expected that doctors should also know the contextual realities of patients, be sensitive towards them, and deliver available services to all without discrimination. It was also pointed out that familiarity with him as a nice person with humane attitude, i.e. *manuski*, helps them have faith in him easily, developing a relationship of mutual trust.

They also judged and decided on whether to use the services of a doctor or not based on his moral character and conduct, trustworthiness, truthfulness and credibility.

8..3.3 Interpersonal interaction features

Illness of the self or a family member made people feel vulnerable. The felt vulnerability of patients and relatives increases as the seriousness of the illness increased. During this phase of vulnerability, the interpersonal interaction with the healthcare provider was of value and shaped the experience of seeking care. Some respondents said that half of the illness is cured if the doctor talks nicely. They expected their doctor to be sensitive, sincere, earnest, gentle, polite and confident. A doctor was expected to be a nice person with humane attitude (*manuski*). Doctors who attempted to make them feel at ease and made them feel confident to share their problems and were sincere in listening to their problems are remembered as good doctors.

Their vulnerability and information asymmetry about the nature of illness and disease management approaches made respondents expect a doctor with whom they could have a functional conversation. They expected a doctor from whom they could seek answers to many of their questions and concerns about the illness and the manner of care provided. They wanted a

doctor with whom they felt that there was scope for some negotiation and dialogue on some aspects of the process of care. For healthcare to be considered good, doctors must speak to them politely, satisfactorily and respectfully. At district-level hospitals, they expected some guidance and handholding additionally in navigating the complex sphere of healthcare institutions. Attributes like moral and ethical standards, along with skills and attitudes of the available human resources, were of great value and determined if care would be sought or not from the care provider. Though much of the discussion was doctor centric, they expected these attributes from other health workers too. The right attitude and behaviour of hospital staff significantly shaped the experience of seeking care. There were many medical consultations where respondents experienced the inability to talk in a manner that satisfied their need to understand the nature of illness and prognosis of their disease condition, where concerns and doubts were not answered or explained properly. Such consultations left them dissatisfied and, at times, shrouded in mystery over their own suffering and health.

Insincerity and lack of earnestness of doctors during the treatment of patients come across as indifference towards patients and their suffering. If this insensitivity is coupled with a poor attitude, then such a doctor is considered a negligent doctor. They had experienced and detested the callous attitude of government doctors and hospital staff. Many respondents, had to muster their courage when they enquired about their health problem and the nature of care provided, and were at the receiving end of the rude and insensitive behaviour of doctors. It is not uncommon in a government hospital that patients are shouted at, scolded, insulted or looked down upon. Feelings of being humiliated, dehumanized, neglected, and uncared for were not uncommon during the care-seeking journey if the care provider is not sensitive and responsive. Indifference and apathy among an increasing number of doctors were pointed to as rapid deterioration of manuski among them. It was said that doctors at government institutions did not have patience and manusaki, i.e. human nature and skills to interact, and they would not talk to the patient or the relatives properly. Nurses were often criticised for being rude to the patient, shouting at them, and being careless, negligent and insensitive.

8.3.4 Social features of the provider

The selfless (free) service provisioning attitude of health care providers, irrespective of their qualifications, was highly respected and valued. According to the people in the village, the doctor residing there makes a significant difference in the accessibility, behaviour and approach of the doctor, and therefore they preferred the residential doctor at PHC. Beyond professional skills and capacity, the doctor should be a nice person. If such a doctor beyond health institutions recognized them, talked to them, and enquired about them, then they remembered such a doctor as a good doctor for a long time. They also believed that doctors from humble socio-economic backgrounds are more likely to understand the contextual realities of the patient while treating, advising and behaving with the patient and their family. Socio-demographic factors like caste, gender, and area of health care providers also shape, to some extent, the choice of the health care provider. These factors are considered media of invoking sympathy/empathy, diligence, and earnestness from the healthcare provider.

While patients used a doctor's social background in selecting their care provider to invoke sympathy, they expected doctors and health workers not to indulge in this kind of practice. They sought care free from preferential, discriminatory and in-dignified ways of treating patients, especially from PHC doctors.

Community members wanted the PHC staff to stay away from the practice of power politics of the village. It was expected that doctors and PHC staff provided equal access and delivered available services to all without any discrimination. Realizing the existing administrative and political structures, some respondents suggested that doctors can and should learn to creatively handle these political interventions and social responsibilities without compromising professional responsibilities.

8.4 Dimensions of quality operating at the level of delivery of medical care /Medical components relevant to understanding quality

8.4.1 Initiation of the care process,

In medical emergencies and prompt access to the care process, quickly starting the treatment for patients was considered of paramount importance. They saw this need for quick access to care as important because in their experience it was fairly common for doctors to attribute poor

outcomes to delays in bringing the patient to the doctor as justification for undesired results. In addition to relieving the suffering of patients, they are worried about undesirable health consequences due to delays in the initiation of treatment. Prompt and frequent attention to patients having a serious illness or during hospitalization is considered good care.

In case of routine illnesses, inordinate delays in getting a consultation with a doctor, especially if the consultation is likely to not be one that assures and treats them in a way that satisfies their queries, are considered unworthy. In addition to prompt initiation of treatment, they also expect a therapy that quickly reduces the total duration of illness. Prompt treatment with high-end medicines reduces the total duration of illness. It also cuts down on much of the indirect costs as it reduces the total cost of travelling, repeated visits and it reduces the total duration of illness.

In case of illnesses requiring major interventions like surgery or other expensive treatment, the dynamic around expected promptness changed. In some situations, community members were suspicious of the institution's motives especially in the case of private hospitals, that started a procedure or operation without trying out medicines and other conservative treatments.

8.4.2 History taking and listening to patients/consultation

Community members repeatedly mentioned the importance of feeling satisfied with a consultation. This satisfaction was anchored in the nature of medical consultation with a doctor. The universal expectation was that doctors should give adequate time. People expected time from a doctor so he or she understood the patient's problem by listening carefully to them and asking them questions. In a medical consultation, they expected the doctor to give them adequate time, listen to their problem, enquire about the situation, take the history of illness, and perform a clinical examination.

Consultations, especially in government hospitals were not in accordance with their expectations. OPDs were overcrowded, and with much fewer doctors, the medical consultation in government hospitals were invariably very unsatisfactory and of very short duration. It was difficult for them to trust the treatment offered without listening to the problem of the patients. This was one of the key reasons for seeking care from private clinics and hospitals where they were willing to spend money on consultations where their problems would be heard, before decisions were made on

the treatment. However, even in private sector clinics and hospitals, many of them could not get satisfactory consultations despite spending large sums of money on fees and waiting for doctors. Specialist doctors charging huge consultation fees also did not give them adequate time; they did not hear them out completely and did not answer their questions.

Consultations in which they came out feeling dissatisfied with the doctor's engagement, were very unsettling, and taking treatment based on such consultation kept them in a constant state of uncertainty and apprehension about their problems. Would they be taken care of adequately, since doctors had neither heard them out nor understood the problem adequately. It appeared that even if doctors were not busy, like in the PHC or in private sector clinics, there was a tendency to be done with the consultation quickly, which to the patients was not reassuring.

8.4.3 Clinical examination

In addition to listening to the patient's problem and history taking, a clinical examination also formed part of the medical consultation. Patients expect a clinical examination during the consultation, to ascertain the nature, extent and implication of illness and hospitalization for evaluating the progress of health and the effect of medicines. Medical consultations involving thorough examination were seen as essential for the treatment to be effective. Clinical examinations were the doctor's attempt to understand the nature of the illness and reflected the doctor's sincerity in understanding the health problem and solving it.

While reflecting on experiences of seeking care, expressions like 'doctors did not even touch the patient' were invoked by respondents to convey a poor form of the medical care process. At the level of PHC, thorough clinical examination was offered to some patients, and it was avoided in case of others. This was seen with suspicion of discrimination. Satisfactory consultation involving a thorough clinical examination of the patient was seen as a better form of medical care and an essential component of quality medical care.

Highly paid consultations from private doctors and specialists at times were done without any clinical examination of patients, and such experiences were remembered as inadequate medical care. Cursory or no clinical examinations were, in some cases, sufficient grounds for them to change care providers.

8.4.4 Diagnosis and prognosis

There was not much insistence or curiosity about knowing the diagnosis in most people for most of the common illness episodes. In the care process, if a doctor needed some diagnostic tests, then it was expected the decisions on the same be made quickly, and the treatment should be offered as early as possible. However, they were also wary of irrational diagnostic tests being prescribed in private hospitals. Though they did not expect a diagnosis that gave them a name for the disease or condition, respondents said that they expected an explanation of the disease condition.

However, in the case of chronic or intractable disease conditions, they were keen on knowing the diagnosis. They sought places where there was the possibility of getting the correct diagnosis and rational treatment. In such a chronic and intractable condition, they expected doctors to tell them about the disease's prognosis and the success rate of the treatment they were offering. Such information helped them make an informed decision to take treatment as it involved investing money, time and effort.

Different diagnoses being offered for the same condition by other doctors was difficult for respondents to comprehend. In the event of such differences of opinion they believed that the most reliable diagnosis would be obtained at government hospitals. The private sector was likely to exploit the situation to offer diagnosis that would fulfil their profiteering motives

For some patients, several specialist consultations with multiple follow-up visits from each consultant also did not result in any diagnosis of their disease condition. Such consultations where none of them offered a diagnosis, or were explained the prognosis of the illness, made community members feel disheartened. Such a situation of no diagnosis and no relief from symptoms was very frustrating for them. It kept them in the perpetual dilemma of whether to search for another doctor or to live with their suffering. Different treatments without significant results exhausted time, effort and money.

8.4.5 Treatment

In routine illnesses, while seeking care at the block or district town, they expected prompt treatment with high-end medicines to reduce the total duration of illness. It was believed that

high-end medicines would cut down much of the indirect cost as it reduces the total cost of travelling, undertaking repeated visits, different medicines or treatment regimen, and reducing the total duration of illness. People usually expected early relief from symptoms; however, when the reason for the long time needed for treatment was explained to them properly they were accommodative of the long duration of treatment.

The universal expectation was that treatment be effective in delivering the intended result. Respondents expected that the treatment be 'needed and rational'. In case of serious illness or multiple co-morbidities, the expectation was for comprehensive treatment of all co-morbidities so that patient's health was restored. The doctor writes the prescriptions and explained where to bring the medicines from, the probable costs, and sometimes the purpose of the medicines used. They wanted the medicines especially IV medicines and fluid, to be administered without delay.

If the treatment offered the possibility of flexibility in getting admission, getting procedures and surgeries on preferred dates, and was according to their demands in terms of specific medicines or formulations, injections and procedures, etc. the community members were more appreciative of it

During an emergency, demonstrated urgency and effort on the part of the doctors and other personnel in providing treatment and relieve the patient's suffering was an important reassurance. During hospitalization, they expected regular, timely and frequent attention, examination and monitoring of the patient's health condition. The treatment was expected to be appropriate and dynamic according to changing state of the disease. Therefore, timely change in treatment, if needed, was considered essential. They expected doctors to be available whenever the situation required them to be there or till the patient was stable.

Discharge from the hospital or treatment was an essential aspect of the care-seeking journey. Timely discharge was expected from hospitalization care after relief from the symptoms. In case of serious or life-threatening conditions, they expect discharge after complete recovery from illness. Untimely discharge before complete recovery from illness could push the patient to search for other care providers. They expected discharge to be accompanied by appropriate advice to be followed by the patient at home. In some cases, referral advice on discharge to visit other necessary care providers to complete the care process and restore health. Delayed

discharge, especially from a private hospital, if treatment could be taken at home, had financial implications and therefore was considered unethical.

One of the components of their care-seeking journey was the experience of avoidance, reluctance and denial of care, especially from lower levels of institutions and, in some cases, from tertiary and speciality hospitals as well. The avoidance or refusal of care had serious implications for patients in the form of living with suffering, aggravation disease conditions and additional efforts and costs as patients had to be taken to an alternative care provider.

Limited treatment options provided by qualified health care professionals where basic/ regular emergencies are also not addressed, such experiences of refusal and avoidance were undesirable aspects of their care-seeking journey. Many times incomplete or partial treatment was provided from private speciality hospitals. Such incomplete or partial care was due to the reluctance of doctors to seek opinions and advice from other professionals for fear of losing patients and, in turn, revenue. Therefore, in addition to what is done in the care process, which necessary things were avoided or missed in the care process also mattered to patients and their wellbeing.

The OPD treatment involved two types of experiences. At PHC, they experienced the same medicines and tablets being given for the different kinds of illnesses. Therefore, patients doubted their effectiveness and appropriateness for disease. At GPs clinics, they received prescriptions with a long list of medicines. They were doubtful of the value of these medicines and considered many of those medicines as unnecessary. They also informed that such a long list of medicines with unnecessary medicine is due to the widespread practice of commissions and kickbacks or stakes with medicine stores.

The phenomenon of unnecessary treatment involving unnecessary diagnostic tests, medicines, admissions, referrals, procedures and surgeries was well-known among the community, and this practice was suspected in the private sector. These unnecessary treatment interventions were considered irrational, unethical and immoral. They informed that the possibility of getting the correct diagnosis and rational treatment was in the government sector. However, their healthcare utilization patterns and knowledge about widely prevalent irrational medical practice in the private sector give an impression that rationality of care becomes a concern only in case of chronic and serious health conditions.

The nature of treatment choices used by private hospital doctors of doing advanced procedures and operations without trying out a medical and conservative line of treatment was pointed out as an irrational medical practice. Some respondents highlighted discretionary medical practice among private hospitals, especially doing only those operations and procedures which will fetch them more money without putting in much effort. People reported this practice among private doctors as undesirable practice.

Tubular vision during treatment with a specialization focus, to the detriment of the patient's overall health, was considered a hazardous form of treatment. in a case of a post-traumatic hemiplegic patient remark from a neuro-surgeon, 'he is a specialist of the brain, and he is treating patient's head injury, so he is not answerable to paralysis in limbs' conveyed the need to ensure the overall health of the patient.

Non-involvement or calling in other therapeutic professionals or relevant specialists for better management of illness and increasing patient's overall wellbeing was considered as wrong behaviour of expert professional. There was also a case where a patient's consent for surgery was for a particular doctor, which was not honoured. A doctor intentionally harming the patient or contributing to the deterioration of his health is considered a serious breach of professional integrity.

8.4.6 Counselling

Time given for satisfactory information and counselling was considered as valuable as medicines. Patients and their families were in a lot of suffering with illness, especially in the case of chronic intractable illnesses or illnesses causing disability or impoverishment.

Despite consulting best of the doctor, visiting best of the institutions, and spending huge amounts of money, time and energy, they were still living with suffering. They were in a state of confusion about the further course of action. Unsatisfactory medical consultations from doctors were part of the problem of their misery. Adequate counselling of the patient by treating doctors and wherever relevant from a trained counsellor was missing in their care-seeking journey.

8.4.7 Overall consultation experience

There were experiences of a six-hour wait to see a doctor, which was followed by six minutes of consultation, where the doctor did not even touch the patient. This kind short consultation with a complete lack of warmth, caring and sincere attitude was pointed out to highlight insensitivity of doctor.

They expected consultation involving explanations about nature of the illness to the patient; the line of management; possible treatment alternatives, with their merits and demerits along with success rates or failure rates of those modalities; available treatment options; how it might benefit in relieving suffering; the nature and duration of treatment given; how medicines are to be taken; the precautions to be taken during treatment; possible side effects; and disease aggravating or relieving factors etc. They also expected flexibility of asking some additional information and queries to the doctor; flexibility of demanding some clinical examination.

Treating doctors were expected to be serious about attending to a patient's in order to resolve it. It was expected that treating doctors would give them a choice and help make an informed decision after explaining the disease and its prognosis. Reassurance of recovery and improvement, or at least sincere care from the doctor, was considered very important during treatment by the patient and attendants. A consultation involving these elements was an enriching and empowering experience for the patient. This practice made them feel treated with some respect and dignity. This practice enabled, empowered and motivated them to take an active part in healing themselves.

There was a mismatch between expected attention, required attention and actual attention received by the patient from doctors and nurses. Balancing these mismatches helps in improving the experience of seeking care for patients. A good consultation was expected to convey limitations of personal or professional capacity, including inadequacies of scientific knowledge in dealing with the health condition that is being treated so that patients and family members (especially in the case of child patients) can cope with it in a better manner. Maintaining patients' dignity during the entire care-seeking journey was also essential for it to be considered good quality health care.

8.4.8 Post-treatment advise to be followed at home

Post-treatment advice is something that patient takes home and lives with for a long time. Therefore, it shaped the experience of care-seeking. They expected appropriate advice to be followed by the patient at home to avoid complications, worsening disease and improving health. As post-treatment advice has implications on health, it mattered to them, especially if it compromised their health. No advice from the doctor for the physiotherapist and speech therapist, not even the suggestion for doing massage and movement of limbs, had resulted in contractures in the limbs of a paralysis patient. Sometimes the advice is inadequate, and sometimes it is wrong and motivated.

In cases of undesirable treatment outcomes like disability or death, it is very important to have appropriate discharge accompanied by counselling and the appropriate closure of the case. In the absence of this counselling and closure, there is a possibility of patients and relatives blaming themselves for not having done enough or for not having done something needed, and then they have to live with the guilt for a long time.

8.4.9 Referral

Referrals constituted one of the common experiences during care-seeking journeys. The nature of referral given has to be considered for assessing its rationality in terms of its timing, reason and referred institution's ability to address the problem. The patient’s experience during the referral process is shaped by the preparation and treatment given before referral, treatment and care provided during transportation for referral, provision of adequately equipped transportation medium, necessary medical records while referring, and intimation to referred institution. Follow-up of referred patients and functional reverse linkages between two referring institutions are useful in making better use of the practice of referrals and available resources efficiently.

People believe that many a time, referrals are done to avoid the effort involved in the required care. It was told that referral is a way of refusing care to the patient. They had experienced doctors using referrals as a punishment strategy for patients or relatives - especially those who demand accountability and answerability from the doctor. They were familiar with the experience of referrals being used to avoid responsibility- Doctors are in a hurry to get rid of

patients from the institution as quickly as possible. Referrals were also used as a means for earning commission through cut practice.

The practice of unnecessary referrals from qualified doctors and healthcare institutions for simple and common health conditions was seen as a mark of poor services. Unnecessary or delayed referrals and motivated referrals for cut practice were also reported as undesirable.

In most of the referrals from the PHC, no advice is given on where to go in block town; neither is there a referral slip given, nor do institutions where patients are referred ask for any referral paper. Referrals are advised in a manner that they are no different from any layperson advising you to go to the hospital to take treatment. There are no records given, no specificity in advice, nor is there any care ensured during the intervening period required to reach the referred institution. Dumb referrals are those where it is not even ascertained if the services /facility for which the patient is referred is available and functional at the referred institution.

None of the community members had an experience with a well-equipped ambulance with an on-board doctor and an emergency treatment facility. Therefore, it was beyond their imagination to expect or comment on.

8.4.10 Results

Expressions like 'if we get relieved from the symptoms, then we call that as good treatment' was widespread. With treatment, if they recovered from the disease and were free from suffering, then they considered treatment was good. This relief from suffering, if offered faster in a manner that cuts down the total duration of treatment, saves their costs further, then such a faster relief from symptoms was appreciated further.

In the absence of a complete cure, the nature and degree of relief offered were used to evaluate the care-seeking experience. Partial and short-lived relief from symptoms despite completing prescribed treatment disappointed many respondents. Non-relief or partial relief from symptoms was considered a wastage of money.

Outcomes of treatment like no relief from a health problem, partial relief, delays, further complications of health problem, high costs, disability and death were undesirable and shaped their assessment of the treatment.

8.4.11 Inter-personal interaction

It was expected that doctors and other hospital staff behave humanely and politely throughout their treatment process. Some seriousness about attending to a patient's ailment and intervening to relieve it made them feel confident. They considered promptness in the care process critical, especially during an emergency.

They expected medical consultations where adequate time is given to discuss the nature of the illness, history taking and clinical examination. The lack of sincerity in their approach and impolite or unkind behaviours from health workers was hurtful. Disrespectful comments or if healthcare providers made them, especially women, feel unsafe, then such care providers were avoided.

8.4.12 Overall judgement

Treatment which involved lower expenditure and lower opportunity costs was valued as better treatment. Treatments with higher costs, especially causing bankruptcy or impoverishment, were considered bad as that impoverishment pushes the patient or entire family into vulnerable situation and makes them susceptible to ill health. Any kind of healthcare they expected to be provided in a dignified manner.

A satisfactory experience of taking treatment was when they felt that doctors were in not in a hurry to get rid of them from hospitals. They expected their treatment-seeking experience from a doctor to be more enabling. Some experiences where they felt being cornered into a situation of helplessness and exploited by the doctor in that vulnerable situation were considered immoral.

They were receiving treatment in the context of medical malpractice -where the practice of commissions, kickbacks and unnecessary medical/surgical interventions are widely known. Such a context made them feel insecure while taking treatment. Sometimes, they could recognize

unethical practices by doctors to earn more money and were helpless in that situation. The feeling of being cheated by the doctor in the care process was demoralizing.

Insensitive and irresponsible doctors, especially from government hospitals, make them go to the private sector and expensive treatment from the private sector pushes them into severe poverty. This painful experience of impoverishment is clearly due to the denial of care from government hospitals. Avoidance, denial or refusal of care was considered inhuman.

8.5 Phases of care seeking journey and community perception of quality in health care

The methodology adopted for this study, analysing care-seeking journeys proved to be very useful in capturing perceptions of quality. The enquiry and examination of care-seeking journey in a community setting provided additional insights that would be missed in patient's responses in a hospital setting. Care-seeking journey as an important methodological tool to study perceptions of quality, offers advantages over structured questionnaires with pre-selected variables to ascertain perceptions of quality and satisfaction with quality of services. It has more potential to capture felt-needs of the community and give them more scope to voice their expectations. However, using the care-seeking journey as a methodological tool requires one to engage with the complexities of qualitative research and the interpretation of findings. Study of community perceptions of quality is the need of the hour and is a necessity especially with the emerging trend of using approaches of Coproduction and LHS in health systems research and for improving quality in healthcare.

Each care seeking journey has different phases, in each of which, different factors are weighed by patients and their families to decide on what health care to resort to and where. Experiences and reflections on those experiences of care in each of these phases bring out different sets of issues relevant to understanding of quality in health care.

The first phase is contemplation, preliminary enquiry, information seeking and discussion on whether and where to seek care. Though this is referred to as the first phase of care seeking journey, some of these issues are constantly contemplated throughout the care-seeking, especially if the care provider has to be changed or if a referral is advised and even after the care-seeking is over.

This phase is shaped by various factors like who is ill? - if it is a new-born or very young child or earning member of the family or elderly person in the family, then consideration about whether and where to seek care changes accordingly. In case of emergencies – like major accidents, snake bites, poisoning, child birthing etc. - the decisions must be made quickly. The nature and duration of the illness also affect the choice of care provider and evaluation of care received.

Factors that became relevant for quality in healthcare based on this first phase of care seeking journey included- treatment options available; reputation and fame of the provider; anticipated or projected costs; accessibility and convenience of possible options; time required to access and time required to complete the treatment; experiences of others with similar health conditions etc.

After the first phase there is the experience of care-seeking from one or multiple providers. Experience with one provider could be a single episode of care seeking or be short single interaction or multiple interactions of OPD / IPD care.

Experience with multiple providers could be because of referral from lower level health care providers or it could be due to the choice of the patient due to non-relief from symptoms, the most common reason for using multiple providers.

Factors that emerged as relevant for understanding quality in healthcare based on this second phase included - relief from the symptoms; comprehensiveness of care provided; cost of the care; assurance provided of better outcomes; dignity and self-respect while using the care services; well informed care- where satisfactory interaction with care providers is possible; convenience of using the services – access, timing, opportunity costs of using the care, all care needs are addressed under one roof; quickness of initiating the care; rime needed for the care provided; number of attendants required during the care process; possibility of meeting the basic necessities like food, toilet, bating, stay etc of patients and attendants during care process; comfort of services offered; scientific care; confidence of care provider; sincerity, earnestness and efforts of care provider; empathy and understanding of care provider during treatment; availability of demonstrable evidence of cure; efforts and sincerity in care provided; availability of ancillary support services like food, linen etc; availability of arrangements for attendants etc.

The third phase of care seeking journey is the post-use reflections of the experience and decision made during the care seeking journey. Factors that emerged as relevant for understanding quality in healthcare based on this third phase included- access to services should be as close as possible. Most common speciality services should be available at the block town level; improving infrastructure and amenities along with the availability of human and material resources in public sector hospitals; improving attitudes and behaviours of health workers; accountability and grievance redressal mechanism for all health services or in all hospitals.

8.6 Summary of Community perceptions

Effectiveness of services, convenient accessibility and affordability (free or economically priced), are three important priorities for both the communities with regards to dimensions of quality in healthcare. The attributes of effectiveness, accessibility and affordability of services are linked with each other. It emerged from the community and individual narratives that ineffective services meant wastage of time and money; unaffordable services were just inaccessible and meant forgoing treatment despite continuing suffering. Therefore, effectiveness of the service would not count for much if it is unaffordable. Free and effective services that are physically difficult to access resulted in patients and their families incurring huge opportunity costs due to the inconvenience of usage, and hence were of little value.

The focus on these factors differed with nature/seriousness of illness. Routine and minor ailments requiring low cost of care (direct plus indirect cost) made it possible for the relatively better-off, members of the Maratha community to demand dignified and respectful services since they could afford to pay. This was reflected in their preference for private GPs and specialist consultations. The convenience and promptness of services provided in GP clinics in the nearby block town were valued by the both the communities, though community members desired that such services be available in their village round the clock. For the ‘Mang’ community members the services from GPs of nearby town were unaffordable and had to be used very judiciously despite their persistent illness and suffering.

However, the dynamics of care seeking changed with chronic and serious illnesses. Effective and free or affordable services are important priorities here, and needed to be supplemented with adequate information sharing and satisfactory counselling. Comprehensive management of co

morbidities in a scientific manner to restore health was appreciated. People preferred services where healthcare providers assured them of outcomes that restored health to the maximum possible. Documented evidence of success in treatment, or information of providers and institutions reputed for their effective care enabled the community to make decisions about seeking care. Government hospitals were the preferred institutions of care for both communities, but it was predominantly the 'Mang' community who were dependent on it and the 'Maratha' had some flexibility, using services from private sector hospitals as well. Services for chronic and serious illnesses requiring specialists were available only in the distant district town making accessing these services inconvenient and expensive. Therefore, having a health service system where the nearby block town catered to most of their specialist care requirements was important to community members.

Care which lacked warmth and respect, was not appreciated by anyone, however the members of 'Maratha' community emphasised on it more frequently as compared to the Mangs. Given their better socio-economic position the Marathas felt entitled to respect as opposed to the 'Mangs' who valued and emphasised the need for free healthcare services. Health care services with lower opportunity costs; and hospitals that provided free medicines, referral transport and food were valued as these facilities made it possible for them to muster the courage to use free services of government hospitals and get required medical care.

8.7 Discussion: The Way Ahead in Research and Practice

8.7.1 Research on community perceptions

Not all perceptions of the community are rational or are feasible to follow up on through interventions to improve quality of care. Some perceptions are practically impossible for providers to implement and may not be agreeable to the providers and institutions. Sometimes these perceptions and expectations may be in contradiction with scientific medical practice.

Therefore, it is important to find common ground between community perceptions and expert-rated quality constructs. Areas with mutual agreement and preference can be taken up for the implementation of quality assurance programs on a priority basis. Research efforts should focus on identifying the felt needs of people regarding the quality of services that they want, along with how healthcare providers think of the quality of services that they are providing and what

their concerns about quality are, and what they consider priority areas of interventions for quality improvement. Besides providers and users, the third stakeholder is the third-party payer–governments and insurance companies. Their expectations and views on quality, the priority they accord to different healthcare needs and healthcare interventions, the legitimacy that they accord to different quality assessments, accreditation and improvement mechanisms, etc. shape the quality of service systems and policies related to them. Therefore, all these three groups of stakeholders have to work together to build institutions and their mechanisms along with the necessary human, monetary and material resources to ensure quality health care for all.

Policy makers and health systems researchers have to factor in this need for triangulation or interaction across the various actors for designing health systems and policies related to them. Ritu Priya (2012) has analysed the various ideological perspectives that went into policy making for health services development in the post-Independence period in India and shows how they hinged on diverse perceptions of 'quality of health care systems'. She further relates these to the public's experience of what was developed through planned government efforts, illustrated by insights from a study on perceptions of migrant construction workers from a dalit community (R. Priya, 1995, 2012)

There is a need for further research on comparing these dimensions across different social groups. The historical backgrounds and lived realities of different communities and in diverse locations vary very significantly in India. Therefore, understanding what matters to these communities about health services and its quality need to be studied for addressing it effectively.

Relative weightage of different dimensions identified as community perceptions of quality is an important question that needs much more research since it is insufficient to list and enumerate these issues in the quality assessment and assurance framework. It was observed and conveyed by people that the relative importance accorded to these factors is different. Therefore, further research is required in identifying how different communities value different dimensions of quality. Community perceptions of quality would be helpful in building a socially relevant framework of quality assessment and assurance and developing indicators for quality assessment.

8.7.2 Emerging Approaches

Over the last two to three decades quality assessment and accreditation programs are promoting compliance and improvement of organizational and care standards. After the Global North, many countries of the South are adopting accreditation systems for improving clinical processes, organization cultures to improve patient safety and health outcomes. Greenfield (2021) identified 97 countries having some kind of accreditation program and about 53 accreditation agencies providing accreditation services. Strategies like effective organizational systems and care processes, human resource management systems and better clinical performance outcomes have had a positive impact on the healthcare services provided. In addition to improving the performance of a participating institution, accreditation systems have led to evolution of a common language and understanding, expectations, standards and forums for quality in healthcare. They have enabled dialogue within, and across, professions and organizations; led to establishment of networks and knowledge distribution (Greenfield et al., 2021).

Some of the common features of these accreditation programs include establishment of a set of standards and using them for assessment; enable institutions to self-assess against those standards; external assessment through surveyors; grand accreditation status etc. External evaluation programs continue to be a predominant strategy used in many countries for assessment and accreditation of quality of healthcare organizations or services.

Different stakeholder groups have differing views on the value of accreditation programs. Health professionals and their representative bodies have been a divided house on the value of accreditation programs with 55% each supporting it whereas 60% and 43% each simultaneously raised concerns over its value. Around 25% of the patients were supportive of accreditation programs whereas 38% were doubtful about the value of such programs (Greenfield et al., 2021). Stakeholders differ in opinions on the issues like appropriate design, implementation of program, public reporting of results as well as their definitive impact on improving the quality of health services (Hussein et al., 2021). The International Society for Quality in Health Care (ISQua) through the ISQua External Evaluation Association (EEA) has standardized accreditation design and processes, and facilitates the global community in practicing accreditation while ensuring some comparability across different accreditation programs.

Resource constraints and under-developed regulatory environments present clear challenges to effective uptake and diffusion of accreditation programs (Braithwaite et al., 2012). Apart from the small stimulus provided by medical tourism there hasn't been much incentive for voluntary uptake of accreditation programs in developing countries. Statutory quality assessment and accreditation programs in LMICs are often based on prominent transnational programs and are donor driven. The influence of commercial and political drivers on the expanding accreditation economy has come under scrutiny (Mansour et al., 2020). The evidence on value and utility of accreditation programmes is inconsistent, giving an impression that proponents and opponents interpret selectively to validate their existing perceptions regarding the accreditation economy (Hinchcliff, 2021).

Denmark's National Quality Program (NQP) of 2015 adopted continuous quality improvement while phasing out accreditation of public hospitals. Since the establishment of the NQP the indicator results have improved in several important clinical areas. This development has opened the window for further scrutiny of the value of accreditation programs (Uggerby et al., 2021).

Shifts in understanding about the accreditation programs and expectations from these programs both on the part of governments and the public continue to remain a challenge for accreditation systems. With emerging health problems; new technological solutions available along with dynamic scientific evidence base for organizing health services, and availability of resources for healthcare services are evolving continually which makes the job of accreditation systems difficult. Harmonising divergences in government policies on healthcare standards and standards prescribed by international agencies like the International Standards Organization (ISO) and ISQua, poses additional challenges for accreditation programs. These contextual changes make refining/updating program purpose and demonstrating value and connection to patient outcomes an important challenge for accreditation systems (Greenfield et al., 2021).

Digital health interventions are increasingly changing the landscape of medical practice and organizational practices in healthcare institutions and would demand and enable further restructuring of accreditation systems. Web based systems facilitate hybridized quality assessment processes, involving varied combinations of announced and unannounced, in-person and remote methods. Real-time availability of information feeding in to decision support

dashboards may make work of accreditation agencies very dynamic enabling regulatory escalation if performance thresholds are breached in real-time. Deep learning algorithms would identify unwarranted clinical variations and might enable accreditation programs to identify and measure high-value care, both within and across organizations. How this emerging knowledge is democratized or commercialized and used by health system architects and to what objectives e.g. better healthcare organizations or improved population health remains to be seen (Hinchcliff, 2021).

Standards are the foundation in accreditation and quality improvement systems. These standards are set by healthcare professionals and regulators. With increasing recognition of importance of patient perspective for understanding quality and acceptability of services, standards are being created based on patient perspectives. Patients are the only ones who have access to the entire experience of care- from self-care, primary care in communities through hospital care to rehabilitation and follow up. In contrast, health professionals experience only a part of the patients' journeys once they are in the health care system. With the broad experience of healthcare system components, patients are in a unique position to contribute to the understanding of quality in healthcare and to the standards for quality assessment and accreditation. Patients can contribute immensely to decide what is desirable and undesirable; what is accessible, convenient, comfortable and timely health service. It is for patients to inform whether they were adequately heard and understood; informed and engaged in decision making on treatment choice and the outcomes to pursue along with acceptable risks; and what constitutes respectful and dignified healthcare service delivery (Mainz et al., 2022). To accommodate these concerns, Patient-Reported Experience Measures (PREMs) and Patient-Reported Outcomes Measures (PROMs) emerge as a means to assure that the patient's voice is an integral part of accreditation systems (Roe et al., 2022).

Inclusion of patient rated outcome standards though useful to accreditation systems, is insufficient. Reviews of the benefits of accreditation have provided mixed results. Therefore, the next step for external evaluation bodies and regulators is to go beyond patient'-reported outcome standards, to accommodate people-developed standards. This implies standards will be coproduced by the people as users of healthcare services. The future of standard development

will be co-design and coproduction with healthcare users so that the standards are appropriate and relevant for people in accordance to their contextual reality (Lachman & Nelson, 2021).

Over the last century, the measures for quality in healthcare have taken many different forms and shifts. Questions about quality in health care, methods and tools used for assessment, and accreditation and actions used for quality improvement work have all undergone change. Paul Batalden and Tina Foster (2021) have analysed evolution and developments in quality of healthcare and proposed three critical phases of this discourse on quality of health care. These three phases have not supplanted each other, but they have been layered one upon the next, over time. Each of these phases brought in new thinking, change of opportunities and also its own limitations.

Historical phases of work to improve quality include the following:

Quality 1.0: Thresholds: Standardization and Accreditation.

The pioneering efforts on quality of health care services focused attention on ensuring a 'basic floor' for hospital addressing the question, 'How might we establish thresholds for good healthcare service?' Many initiatives of this phase have used strategies like continuity of quality patient care, human resource management, clinical leadership, patient safety systems, clinical review structures and processes supporting safety and clinical organization. These have benefitted positively from accreditation work processes. Mixed and limited positive effects of the quality improvement initiatives were observed on the actual delivery of scientifically informed patient care, consumer participation and clinical performance more generally. Today these are important elements in any comprehensive program to improve health-care services. The strategies originating in this phase focus more on bureaucratic formalities, especially when professionals get accredited, ignoring factors relevant for development and operation of effective systems of disease prevention and management to improve outcomes for patients and families (P. Batalden & Foster, 2021).

The second phase is, Quality 2.0: Organization-Wide Improvement Science Systems. Inspired by the work of W. Edwards Deming and Kaoru Ishikawa and Joseph M. Juran, focus of quality related initiatives shifted to the processes and systems of production, cutting down on unwanted

variation, inculcating pride in the work, and collaborative work practices. This contributed immensely to quality in healthcare. ‘Company-wide’ or ‘enterprise wide’ improvement in quality and efficiency were objectives of the methods of work analysis, measurement, change and improvement. The driving question of the second phase, Quality 2.0, ‘How might enterprise-wide efforts improve our systems for prevention and management of disease and disease-related illness?’ helped gain additional insights for the improvement of quality. Under this phase emerged strategies for measurement of end results of the care process including patient satisfaction for quality assessment and accreditation (P. Batalden & Foster, 2021).

The new and emerging phase, *Quality 3.0, is of Coproduction of Healthcare Service and Health.* Paul Batalden (2018) points to a new question, an urgent one, ‘How might we improve the value of the contribution that healthcare services make to better health?’ (P. Batalden, 2018). Paul Batalden and Tina Foster (2021) urge fresh examination of two terms in this question ‘service’ and ‘value’. As against product, providing a service involves two parties working together interdependently. The work of health-care professionals and those they serve seems to be predominantly linked to ‘service making’, with some relevance of ‘product thinking’ as well. Therefore, in health services coproduction is integral however, during this coproduction, the value and contribution of each party may vary greatly. Therefore, it is pertinent not just simply to coproduce but to ensure authentic interdependent work, which improves the quality and value of those services. Closer examination of health services shows that there are ‘activities’ and ‘relationships’. These are connected by knowledge, skill, shared power as well as willingness to be vulnerable on the parts of both, professionals and beneficiaries. The ‘kin-ship’ as underpinning the interdependent efforts of people—some as patients, some as professionals—in Quality 3.0 might be of some importance for addressing the current schism between individual and community health (P. Batalden & Foster, 2021)

The earlier efforts on quality improvement accreditation focused on adverse events. The efforts were made at different levels like individual staff, team, work, task and technology, environment, organization and management, institutional context and patient to identify factors relevant for quality and for intervening to assess and improve quality. These efforts have contributed to improvement of health services with better quality healthcare. The new approach requires us to take on the entire ‘lifespan’ of an event rather than a isolated incident and makes it essential to

include perspectives of individuals, families and communities to find problems as well as resilience and strengths of quality of services provided. The future of quality related work in healthcare with "*a shift from the 'enterprise-wide systems of disease management' approach of Quality 2.0 to a focus on the 'coproduction of health' in Quality 3.0 requires that we consider not only individuals and populations but also the communities served. The reality of the daily work must now integrate and honour the knowledge, expertise and assets of people sometimes known as patients and people sometimes known as professionals. Each of these elements is affected by the others: new ways of working require new approaches to professional development; new articulation of social understanding may affect payment and finance*" (Batalden & Foster, 2021, pp-ii14)

Prior to COVID-19, globally, healthcare was facing many challenges including that of poor quality of care. The focus of healthcare systems has been on disease management rather than on promoting health. The resources invested in healthcare service delivery are huge and health systems continue to consume more and more of the gross domestic product in most of the countries. The rising cost of care systems, which are often of poor quality and unsafe, are growing beyond the reach for most people across societies (Lachman & Nelson, 2021).

The COVID-19 pandemic experience shows how policy has not been coproduced with the people affected by the pandemic. On the other hand, the response to the HIV-AIDS pandemic by involving people living with HIV-AIDS has demonstrated the value of grassroots development of policy enabling people to own and implement it. Changes are required in the way governments and health policymakers work. Rather than telling people what to do, a mass movement to produce and protect health is required. There are examples in social care and in knowledge production in health and social care that show that it is imperative to involve marginal social groups to lead and coproduce policy and health (Beresford, 2019; Howlett et al., 2017; Lachman & Nelson, 2021; Radl-Karimi et al., 2020).

Paul Batalden has urged healthcare leaders, providers, communities and citizens to figure out ways of getting more health out of the money invested in healthcare (P. Batalden, 2018). The solution proposed for this is the coproduction of health, healthcare and health science (M. Batalden et al., 2016; Nelson et al., 2016). The interest in a concept of coproduction in healthcare

is increasing. Evidence from many settings like rheumatology (Essén & Lindblad, 2013), inflammatory bowel disease (Crandall et al., 2011), oncology (Basch et al., 2017) and primary care (Fernandopulle, 2017) shows that it is feasible to implement coproduction principles for reducing the burden of illness, treatments and costs.

The core thesis of co-production is that by building on professional and end user collaborative kinship, patients can be supported to manage their own conditions. This especially is relevant and feasible for chronic disease conditions. The goal is to co-create value, going beyond practitioners becoming better at patient-centred care and sharing decision with patient, coproduction processes put together the synergistic effect of user-centred design, technological innovation and human learning. It is worth the effort for the convenience and efficiency they offer to both providers and users of services. Coproduction has the potential to increase patient satisfaction and enabling cost-effective, high-quality care. The opportunities to engage stakeholders including users of health services and communities are increasing with new technologies, therefore health systems have to be open to the potential in these new models of care (Elwyn et al., 2020)

Batalden et al have described the coproduction of healthcare services as 'the interdependent work of users and professionals to design, create, develop, deliver, assess and improve the relationships and actions that contribute to the health of individuals and populations' (M. Batalden et al., 2016). Principles of coproduction demand going beyond passive patient hood to collaboration; and moving away from professional recommendation to engagement so that there is shared decision making and self-management (Swensen et al., 2010). To ensure this, coproduction uses a process and/or technology that leverages users' time, motivation and skills for adding value to the outcome by making it more convenient, efficient and cost-effective (Elwyn et al., 2020).

In healthcare, coproduction demands effort and work from everyone. Patients have to share their concerns and goals, participate in decision making and learn to manage some health problem especially long-term conditions and minor illnesses. It is assumed that patients, attendant, families and people will participate in this new role as people value the control and convenience afforded, as well as the possibility of better long-term outcomes. Clinicians will have to be

curious and engage with about patients' goals and work collaboratively to co-decide and co-design care, so that it can be co-delivered. These new roles require new skills and often significant attitude changes (Elwyn et al., 2020). It calls for simultaneous and synergistic developmental work at policy, organizational, micro-system and interpersonal levels to ensure successful coproduction.

In addition to coproduction, another emerging trend for improving quality of healthcare is that of learning health systems which is inspired from learning organizations. A learning organization was defined as "an organization skilled at creating, acquiring, and transferring knowledge, and at modifying its behaviour to reflect new knowledge and insights". A Learning Health System (LHS) is defined by the IOM as a system 'in which science, informatics, incentives, and culture are aligned for continuous improvement and innovation, with best practices seamlessly embedded in the care process, patients and families, active participants in all elements, and new knowledge captured as an integral by-product of the care experience' (Gremyr et al., 2021). The definition above is comprehensive, but not very specific. With this definition, almost any health system can claim to be a Learning Health System if it has scientific processes, informatics and incentives in play. However, the key differentiating feature is that the focus of the LHS is on collecting data to generate knowledge and applying it to improve practice.

Table 8.1 Characteristics of a continuously learning healthcare system

Domain	Characteristics
Science and informatics	A learning healthcare system continuously and reliably captures, curates and delivers the best available evidence to guide, support, tailor and improve clinical decision-making and care safety and quality.
	A learning healthcare system captures the care experience on digital platforms for real-time generation and application of knowledge for care improvement.
Patient–clinician partnerships	A learning healthcare system is anchored in patient needs and perspectives and promotes the inclusion of patients, families and other caregivers as vital members of the continuously learning care team.
Incentives	A learning healthcare system has incentives actively aligned to encourage continuous improvement, identify and reduce waste, and reward high-value care.
	A learning healthcare system systematically monitors the safety, quality, processes, prices, costs and outcomes of care and makes information available

	for care improvement and informed choices and decision-making by clinicians, patients and their families.
Continuous learning culture	A learning healthcare system is stewarded by leadership committed to a culture of teamwork, collaboration and adaptability in support of continuous learning as a core aim.
	A learning healthcare system constantly refines complex care operations and processes through ongoing team training and skill building, systems analysis and information development, and creation of the feedback loops for continuous learning and system improvement.

Sources: (Gremyr et al., 2021).

LHSs harness informatics, to learn from every patient who is treated. LHS usually involves cycle in which data are collected and analysed to address a question and then fed back into the health system for improvement. This is similar to most common definitions of a quality improvement cycle, such as the plan, do, study, act model. Learning health systems can be conceptualized to operate at different scales and levels. It may operate at the level of a national or international health system or at the level of a provider or a clinical microsystem, such as a speciality team. LHS models have been used to identify and improve gaps in evidence base by conceptualizing LHS at national and international levels (Foley & Vale, 2017).

Foley TJ and Vale L (2017) identified six types of LHS —intelligent automation, clinical decision support, predictive models, positive deviance, surveillance, and comparative effectiveness research as having a broad range of positive impacts across the 6 dimensions of quality (safe, effective, patient-centred, timely, efficient and equitable). While the research findings are relatively new and in need of rigorous evaluation through multiple research studies, it was understood that the LHS also had the potential to negatively impact quality (Foley & Vale, 2017).

There is growing interest in using the concept of the LHS to integrate different knowledge domains for achieving better health. LHSs can harness co-production and are used to identify principles that can enhance value co-creation: (i) use a shared aim, (ii) navigate towards improved outcomes, (iii) tailor feedback with and for users, (iv) distribute leadership, (v) facilitate interactions, (vi) co-design services and (vii) support self-organization (Gremyr et al., 2021).

Both, the coproduction and LHS, need to engage with communities, especially marginal or discriminated communities, for making healthcare systems and their quality relevant and valuable. The findings from this study on perceptions of quality of healthcare of the 'Mang' and the 'Maratha' communities from rural areas of a backward region in Maharashtra have highlighted the willingness and desire to coproduce health. The findings give sufficient material and insights for the new approaches of coproduction and LHS. The approaches of coproduction and LHS going beyond patient and family focus, will have to engage with 'communities' to leverage community knowledge systems and resources on health for improving population health and wellbeing. The 'Mang' and 'Maratha' were demanding convenient and accessible healthcare services as close to their village as possible. They were using services of health care providers ranging from traditional healers, doctors of different systems of medicine (AYUSH) to super-specialists from their district as well as from faraway places depending on their illness requirements. This offers important lessons for understanding quality of health care and health systems development. The human and knowledge resources available in communities are beyond conventionally assumed resources like certified doctors and institutions of modern systems of medicine. These will become integral when engaging with communities for betterment of health. All these human and knowledge resources of communities will have to be engaged in coproduction and LHSs for improving health and health services.

Ritu Priya (2022) advocates that Health Systems Research (HSR) and practice need to address the politics of knowledge if a significant movement is to be made towards developing national integrative health systems which are sustainable, cost effective, environment friendly and empowering people. Taking into account knowledge resources and practices around health and wellbeing among people, she recognizes contemporary developments in the scientific domain, with more inter-disciplinary and trans- disciplinary research being institutionalised especially in relation to development studies and sustainability, and suggests that it can lead to a different knowledge generation for health systems development (R. Priya, 2022)

She further points to the difficult and yet much-needed movement away from the paradigm of one knowledge tradition as the 'true' or most valid knowledge, whether developed as a singular science or as an integration of more than one tradition. Acceptance of the legitimacy of co-existence of epistemological diversity and pluralism of health knowledge traditions need to be

engaged with in coproduction and LHSs for developing health systems, especially in developing countries. Only then will it be possible to develop inclusive, sustainable and people-empowering health care systems for the 21st century (R. Priya, 2022).

For them to be considered of better quality, health services systems have to be internally consistent in all their components or constituents from policy making mechanisms and knowledge domains, to organization, human resources, technologies, and practices that can meet expectations and produce the outcome etc. In addition to this, health systems have to function such that there is external consistency with other domains and practices of social, economic, political and environmental aspects of human life. The co-production of understandings of quality and developing its assessment mechanisms appropriately requires a theoretical framework for health systems that locates the collective contextual experience of the intended users of health services as the central concern (Ghodajkar et al., 2019). This study provides an approach that can facilitate such co-production and co-development. It further requires studies triangulating perceptions and experience of professional health care providers and policy makers to generate a holistic approach to 'quality in healthcare’. As the review of literature shows, dominant approaches to quality assessment and accreditation, have not yet adopted such a holistic approach and it is to be hoped that further advances will take place in this regard.

References

A.F., A.-A. (2001). Quality in Health Care: An Overview. In A.-A. A. F. (Ed.), *Health Care Quality An International Perspective* (pp. 15–26). WHO Regional Office for South-East Asia.

Abouzahr, C., Vlassoff, C., & Kumar, A. (1996). Quality health care for women: a global challenge. *Health Care for Women International*, *17*(5), 449–467.

Accreditation, C. C. on H. S. (1996). *A Guide to the Development and Use of Performance Indicators*. Canadian Council on Health Services Accreditation. https://books.google.co.in/books?id=hgbfmwEACAAJ

Aharony, L., & Strasser, S. (1993). Patient Satisfaction: What we Know about and What we Still Need to Explore. *Medical Care Review*, *50*(1), 49–79. https://doi.org/10.1177/002570879305000104

American Medical Association, A. H. C. on the C. on S. A. (1999). Health literacy: report of the Council on Scientific Affairs. *Jama*, *281*(6), 552–557.

Andaleeb, S. S. (2001). Service quality perceptions and patient satisfaction: a study of hospitals in a developing country. *Social Science & Medicine*, *52*(9), 1359–1370.

Anderson, E. W., & Sullivan, M. W. (1993). The antecedents and consequences of customer satisfaction for firms. *Marketing Science*, *12*(2), 125–143.

Anderson, K. O., Mendoza, T. R., Valero, V., Richman, S. P., Russell, C., Hurley, J., DeLeon, C., Washington, P., Palos, G., & Payne, R. (2000). Minority cancer patients and their providers: pain management attitudes and practice. *Cancer: Interdisciplinary International Journal of the American Cancer Society*, *88*(8), 1929–1938.

Arah, O. A., Klazinga, N. S., Delnoij, D. M. J., Asbroek, A. H. A. Ten, & Custers, T. (2003). Conceptual frameworks for health systems performance: a quest for effectiveness, quality, and improvement. *International Journal for Quality in Health Care*, *15*(5), 377–398.

Arah, O. A., Westert, G. P., Hurst, J., & Klazinga, N. S. (2006). A conceptual framework for the OECD health care quality indicators project. *International Journal for Quality in Health Care*, *18*(suppl_1), 5–13.

Armitage, K. J., Schneiderman, L. J., & Bass, R. A. (1979). Response of physicians to medical complaints in men and women. *Jama*, *241*(20), 2186–2187.

Armstrong, G., & Kotler, P. (2007). *Marketing: An Introduction*. Pearson Prentice Hall. https://books.google.co.in/books?id=GEREAAAAYAAJ

Ayanian, J. Z., Udvarhelyi, I. S., Gatsonis, C. A., Pashos, C. L., & Epstein, A. M. (1993). Racial differences in the use of revascularization procedures after coronary angiography. *Jama*, *269*(20), 2642–2646.

Ayanian, J. Z., Weissman, J. S., Chasan-Taber, S., & Epstein, A. M. (1999). Quality of care by

race and gender for congestive heart failure and pneumonia. *Medical Care*, 1260–1269.

Bach, P. B., Cramer, L. D., Warren, J. L., & Begg, C. B. (1999). Racial Differences in the Treatment of Early-Stage Lung Cancer. *New England Journal of Medicine*, *341*(16), 1198–1205. https://doi.org/10.1056/NEJM199910143411606

Baltussen, R., & Ye, Y. (2006). Quality of care of modern health services as perceived by users and non-users in Burkina Faso. *International Journal for Quality in Health Care*, *18*(1), 30–34.

Banerji, D. (1982). *Poverty, class, and health culture in India* (Vol. 1). New Delhi, India: Prachi Prakashan.

Banerji, D., & Andersen, S. (1963). A sociological study of awareness of symptoms among persons with pulmonary tuberculosis. *Bulletin of the World Health Organization*, *29*(5), 665.

Baru, R. (2005). Gender and social characteristics of the labour force in health services. *Exploring Gender Equations: Colonial and Post Colonial India. New Delhi: Nehru Memorial Museum and Library*.

Baru, R. V, & Kurien, C. M. (2002). Towards an Expanded Conceptualisation of Quality in Public Health Services. *Unpublished Paper, Centre of Social Medicine and Community Health*.

Basch, E., Deal, A. M., Dueck, A. C., Scher, H. I., Kris, M. G., Hudis, C., & Schrag, D. (2017). Overall survival results of a trial assessing patient-reported outcomes for symptom monitoring during routine cancer treatment. *Jama*, *318*(2), 197–198.

Batalden, M., Batalden, P., Margolis, P., Seid, M., Armstrong, G., Opipari-Arrigan, L., & Hartung, H. (2016). Coproduction of healthcare service. *BMJ Quality & Safety*, *25*(7), 509–517.

Batalden, P. (2018). Getting more health from healthcare: quality improvement must acknowledge patient coproduction—an essay by Paul Batalden. *Bmj*, *362*.

Batalden, P., & Foster, T. (2021). From assurance to coproduction: a century of improving the quality of health-care service. *International Journal for Quality in Health Care*, *33*(Supplement_2), ii10–ii14.

Ben-Sira, Z. (1980). Affective and instrumental components in the physician-patient relationship: an additional dimension of interaction theory. *Journal of Health and Social Behavior*, 170–180.

Beresford, P. (2019). Public participation in health and social care: exploring the co-production of knowledge. *Frontiers in Sociology*, *3*, 41.

Birkmeyer, J. D., Dimick, J. B., & Birkmeyer, N. J. O. (2004). Measuring the quality of surgical care: structure, process, or outcomes? 1. *Journal of the American College of Surgeons*, *198*(4), 626–632.

Blustein, J., & Weiss, L. J. (1998). Visits to specialists under Medicare: socioeconomic advantage and access to care. *Journal of Health Care for the Poor and Underserved*, *9*(2), 153–169.

Brady, M. K., & Cronin Jr, J. J. (2001). Some new thoughts on conceptualizing perceived service quality: a hierarchical approach. *Journal of Marketing*, *65*(3), 34–49.

Braithwaite, J., Shaw, C. D., Moldovan, M., Greenfield, D., Hinchcliff, R., Mumford, V., Kristensen, M. B., Westbrook, J., Nicklin, W., & Fortune, T. (2012). Comparison of health service accreditation programs in low-and middle-income countries with those in higher income countries: a cross-sectional study. *International Journal for Quality in Health Care*, *24*(6), 568–577.

Brook, R. H., Kamberg, C. J., Lohr, K. N., Goldberg, G. A., Keeler, E. B., & Newhouse, J. P. (1990). Quality of ambulatory care: epidemiology and comparison by insurance status and income. *Medical Care*, 392–433.

Brown, M. L., Potosky, A. L., Thompson, G. B., & Kessler, L. K. (1990). The knowledge and use of screening tests for colorectal and prostate cancer: data from the 1987 National Health Interview Survey. *Preventive Medicine*, *19*(5), 562–574.

Bruce, J. (1990). Fundamental elements of the quality of care: a simple framework. *Studies in Family Planning*, *21*(2), 61–91.

Bruce, J., & Jain, A. (1991). Improving the quality of care through operations research. *Progress in Clinical and Biological Research*, *371*, 259–282.

Bruster, S., Jarman, B., Bosanquet, N., Weston, D., Erens, R., & Delbanco, T. L. (1994). National survey of hospital patients. *Bmj*, *309*(6968), 1542–1546.

Burack, J. H., Impellizzeri, P., Homel, P., & Cunningham Jr, J. N. (1999). Public reporting of surgical mortality: a survey of New York State cardiothoracic surgeons. *The Annals of Thoracic Surgery*, *68*(4), 1195–1200.

Busse, R., Panteli, D., & Quentin, W. (2019). An introduction to healthcare quality: defining and explaining its role in health systems. In *Improving healthcare quality in Europe*.

Canadian Institute for Health Information. (2001). *Health Care in Canada*. https://publications.gc.ca/Collection/H117-1-2001E.pdf

Canadian Institute for Health Information, S. C. (2000). *Canadian Health Information Roadmap Initiative Indicators Framework*. Canadian Institute for Health Information Ottawa.

Care, C. D. of H. and A. (2000). *The Australian Health Care System, An Outline*. Australian Institute of Health and Welfare Canberra.

Carinci, F., Van Gool, K., Mainz, J., Veillard, J., Pichora, E. C., Januel, J. M., Arispe, I., Kim, S. M., Klazinga, N. S., & Group, O. H. C. Q. I. E. (2015). Towards actionable international comparisons of health system performance: expert revision of the OECD framework and quality indicators. *International Journal for Quality in Health Care*, *27*(2), 137–146.

Carlisle, D. M., Leake, B. D., & Shapiro, M. F. (1995). Racial and ethnic differences in the use of invasive cardiac procedures among cardiac patients in Los Angeles County, 1986 through 1988. *American Journal of Public Health*, *85*(3), 352–356.

Carr-Hill, R. A. (1992). The measurement of patient satisfaction. *Journal of Public Health*, *14*(3), 236–249.

Charles, C., Gauld, M., Chambers, L., O'Brien, B., Haynes, R. B., & Labelle, R. (1994). How was your hospital stay? Patients' reports about their care in Canadian hospitals. *CMAJ: Canadian Medical Association Journal*, *150*(11), 1813.

Cleary, P. D., Edgman-Levitan, S., Roberts, M., Moloney, T. W., McMullen, W., Walker, J. D., & Delbanco, T. L. (1991). Patients evaluate their hospital care: a national survey. *Health Affairs*, *10*(4), 254–267.

Cleary, P. D., & McNeil, B. J. (1988). Patient satisfaction as an indicator of quality care. *Inquiry*, 25–36.

Cleeland, C. S., Gonin, R., Baez, L., Loehrer, P., & Pandya, K. J. (1997). Pain and treatment of pain in minority patients with cancer: the Eastern Cooperative Oncology Group Minority Outpatient Pain Study. *Annals of Internal Medicine*, *127*(9), 813–816.

Collins, K. S., Hall, A. G., & Neuhaus, C. (1999). *US minority health: A chartbook*.

Commission, A. (2000). Aiming to improve: the principles of performance measurement. *London: Audit Commission*, *9*, 1999–2000.

Commission, E. (2014). *Communication from the commission on effective, accessible and resilient health systems*. European Commission Brussels, Belgium.

Committee, N. H. P. (2000). Fourth National Report on health sector performance indicators: A report to the Australian Health Ministers' Conference. *New South Wales Health Department, Sydney*.

Committee, N. H. P. (2001). National health performance framework report. *Brisbane: Queensland Health*.

Cooper-Patrick, L., Gallo, J. J., Gonzales, J. J., Vu, H. T., Powe, N. R., Nelson, C., & Ford, D. E. (1999). Race, gender, and partnership in the patient-physician relationship. *Jama*, *282*(6), 583–589.

Coulter, A., & Fitzpatrick, R. A. T. (2003). The Patient's Perspective Regarding Appropriate Health Care. *The Handbook of Social Studies in Health and Medicine*, 454.

Crandall, W., Kappelman, M. D., Colletti, R. B., Leibowitz, I., Grunow, J. E., Ali, S., Baron, H. I., Berman, J. H., Boyle, B., & Cohen, S. (2011). ImproveCareNow: the development of a pediatric inflammatory bowel disease improvement network. *Inflammatory Bowel Diseases*, *17*(1), 450–457.

Davies, A. R., & Ware Jr, J. E. (1988). Involving consumers in quality of care assessment.

Health Affairs, *7*(1), 33–48.

Delivery, I. of M. (U. S.). C. on the N. Q. R. on H. C., Hurtado, M. P., Medicine, I. of, Delivery, C. on the N. Q. R. on H. C., Services, B. on H. C., Swift, E. K., Corrigan, J. M., & Quality, U. S. A. for H. R. and. (2001). *Envisioning the National Health Care Quality Report*. National Academies Press. https://books.google.co.in/books?id=BrBpAAAAMAAJ

Docteur, E., & Berenson, R. A. (2009). How Does the Quality of Health Care Compare Internationally? *Timely Analysis of Immediate Health Policy Issues, a Series of Policy Briefs Produced by the Urban Institute and the Robert Wood Johnson Foundation*.

Donabedian, A. (1966). Evaluating the quality of medical care. *The Milbank Memorial Fund Quarterly*, *44*(3), 166–206.

Donabedian, A. (1980). *Explorations in quality assessment and monitoring: the definition of quality and approaches to its assessment*.

Donabedian, A. (1985). The epidemiology of quality. *Inquiry*, 282–292.

Donabedian, A. (1988). The quality of care: how can it be assessed? *Jama*, *260*(12), 1743–1748.

Donabedian, A. (1990). The seven pillars of quality. *Archives of Pathology & Laboratory Medicine*, *114*(11), 1115–1118.

Draper, M., & Hill, S. (1996). Feasibility of national benchmarking of patient satisfaction with Australian hospitals. *International Journal for Quality in Health Care*, *8*(5), 457–466.

Eddy, D. M. (1998). Performance Measurement: Problems And Solutions: Measuring performance of health plans remains elusive, but not from lack of effort or brains. One expert outlines a strategy to improve our chance of success. *Health Affairs*, *17*(4), 7–25.

Ellwood, P. M. (1997). Shattuck Lecture--outcomes management. A technology of patient experience. 1988. *Archives of Pathology & Laboratory Medicine*, *121*(11), 1137–1144.

Elwyn, G., Nelson, E., Hager, A., & Price, A. (2020). Coproduction: when users define quality. *BMJ Quality & Safety*, *29*(9), 711–716.

Epstein, A. M. (1990). The outcomes movement—will it get us where we want to go? In *New England Journal of Medicine* (Vol. 323, Issue 4, pp. 266–270). Mass Medical Soc.

Escarce, J. J., Epstein, K. R., Colby, D. C., & Schwartz, J. S. (1993). Racial differences in the elderly's use of medical procedures and diagnostic tests. *American Journal of Public Health*, *83*(7), 948–954.

Essén, A., & Lindblad, S. (2013). Innovation as emergence in healthcare: unpacking change from within. *Social Science & Medicine*, *93*, 203–211.

Evans, D. B., Edejer, T. T., Lauer, J., Frenk, J., & Murray, C. J. L. (2001). Measuring quality: from the system to the provider. *International Journal for Quality in Health Care*, *13*(6), 439–446.

Fernandopulle, R. (2017). Primary care needs a complete rebuilding and not just more Renovations. *The Journal of Ambulatory Care Management*, *40*(2), 121–124.

Fiscella, K. (2003). Assessing health care quality for minority and other disparity populations (AHRQ Pub. No. 03–0047-EF). *Rockville, MD: US Department of Health and Human Services*.

Fiscella, K., Franks, P., & Clancy, C. M. (1998). Skepticism toward medical care and health care utilization. *Medical Care*, 180–189.

Fiscella, K., Franks, P., Gold, M. R., & Clancy, C. M. (2000). Inequality in quality: addressing socioeconomic, racial, and ethnic disparities in health care. *Jama*, *283*(19), 2579–2584.

Fitzpatrick, R., & Hopkins, A. (1983). Problems in the conceptual framework of patient satisfaction research: an empirical exploration. *Sociology of Health & Illness*, *5*(3), 297–311.

Flexner, A., Pritchet, H., & Henry, S. (1910). Medical education in the United States and Canada bulletin number four (The Flexner Report). *New York: The Carnegie Foundation for the Advancement of Teaching*, 346.

Foley, T. J., & Vale, L. (2017). What role for learning health systems in quality improvement within healthcare providers? *Learning Health Systems*, *1*(4), e10025.

Garg, P. P., Furth, S. L., Fivush, B. A., & Powe, N. R. (2000). Impact of gender on access to the renal transplant waiting list for pediatric and adult patients. *Journal of the American Society of Nephrology*, *11*(5), 958–964.

Garvin, D. A. (1988). *Managing quality: The strategic and competitive edge*. Simon and Schuster.

Ghodajkar, P., Das, S., Sarkar, A., Gandhi, M. P., Gaitonde, R., & Priya, R. (2019). Towards Re-Framing Operational Design for HFA 2.0: Factoring in Politics of Knowledge in Health Systems. *Medico Friends Circle Bulletins*, *380*, 16–25. http://www.mfcindia.org/mfcpdfs/MFC380.pdf

Gilson, L., Magomi, M., & Mkangaa, E. (1995). The structural quality of Tanzanian primary health facilities. *Bulletin of the World Health Organization*, *73*(1), 105.

Giuffrida, A., Gravelle, H., & Roland, M. (1999). Measuring quality of care with routine data: avoiding confusion between performance indicators and health outcomes. *Bmj*, *319*(7202), 94–98.

Glance, L. G., Osler, T. M., & Dick, A. (2002). Rating the quality of intensive care units: is it a function of the intensive care unit scoring system? *Critical Care Medicine*, *30*(9), 1976–1982.

Goldberg, K. C., Hartz, A. J., Jacobsen, S. J., Krakauer, H., & Rimm, A. A. (1992). Racial and community factors influencing coronary artery bypass graft surgery rates for all 1986 Medicare patients. *Jama*, *267*(11), 1473–1477.

Gornick, M. E., Eggers, P. W., Reilly, T. W., Mentnech, R. M., Fitterman, L. K., Kucken, L. E., & Vladeck, B. C. (1996). Effects of race and income on mortality and use of services among Medicare beneficiaries. *New England Journal of Medicine*, *335*(11), 791–799.

Greenfield, D., Iqbal, U., O'connor, E., Conlan, N., & Wilson, H. (2021). An appraisal of healthcare accreditation agencies and programs: similarities, differences, challenges and opportunities. *International Journal for Quality in Health Care*.

Gremyr, A., Andersson Gäre, B., Thor, J., Elwyn, G., Batalden, P., & Andersson, A.-C. (2021). The role of co-production in Learning Health Systems. *International Journal for Quality in Health Care*, *33*(Supplement_2), ii26–ii32.

Grönroos, C. (1984). A service quality model and its marketing implications. *European Journal of Marketing*.

Group, N. H. M. B. W. (1996). First national report on health sector performance indicators: public hospitals-the state of play. *Australian Institute of Health and Welfare, Canberra*.

Group, N. H. M. B. W. (1998). Second National Report on Health Sector Performance Indicators. *Canberra: Commonwealth Department of Health and Family Services*.

Group, N. H. M. B. W. (1999). Third national report on health sector performance indicators. *Canberra: Commonwealth Department of Health and Aged Care*, 25.

Haddad, S., Fournier, P., Machouf, N., & Yatara, F. (1998). What does quality mean to lay people? Community perceptions of primary health care services in Guinea. *Social Science & Medicine*, *47*(3), 381–394.

Hahn, B. A. (1995). Children's health: racial and ethnic differences in the use of prescription medications. *Pediatrics*, *95*(5), 727–732.

Hahn, R. A., Teutsch, S. M., Franks, A. L., Chang, M.-H., & Lloyd, E. E. (1998). The prevalence of risk factors among women in the United States by race and age, 1992-1994: opportunities for primary and secondary prevention. *Journal of the American Medical Women's Association (1972)*, *53*(2), 96–104.

Handler, A., Issel, M., & Turnock, B. (2001). A conceptual framework to measure performance of the public health system. *American Journal of Public Health*, *91*(8), 1235–1239.

Harrigan, M. (2000). Quest for quality in Canadian health care. *Continuos Quality Improvement*, 34.

Harteloh, P. P. M., & Verheggen, F. W. S. M. (1994). Quality assurance in health care. From a traditional towards a modern approach. *Health Policy*, *27*(3), 261–270.

Hartigan, P. (1998). *Environment, gender and health: Incorporating a gender approach into environmental health work*. Division of Environment and Health. Pan American Health Organization.

Hartigan, P. (2001). The importance of gender in defining and improving quality of care: some

conceptual issues. *Health Policy and Planning*, *16*(suppl_1), 7–12.

Harvey, G. (1996). Quality in health care: traditions, influences and future directions. *International Journal for Quality in Health Care*, *8*(4), 341–350.

Health, A. I. of, & Health, A. I. of. (2000). *Australia's Health*. Australian Government Pub. Service.

Heckman, T. G., Somlai, A. M., Peters, J., Walker, J., Otto-Salaj, L., Galdabini, C. A., & Kelly, J. A. (1998). Barriers to care among persons living with HIV/AIDS in urban and rural areas. *AIDS Care*, *10*(3), 365–375.

Henderson, J., Goldacre, M. J., Griffith, M., & Simmons, H. (1992). Recording of deaths in hospital information systems: implications for audit and outcome studies. *Journal of Epidemiology & Community Health*, *46*(3), 297–299.

Henry, J. (1999). *Kaiser Foundation. Race, ethnicity, & family care: a survey of public perceptions and experiences*.

Hinchcliff, R. (2021). Advancing the accreditation economy: a critical reflection. *International Journal for Quality in Health Care*, *33*(4).

Hock, L. K. (2005). Evolving concepts of quality: The need for a contextual approach to defining quality. *The Singapore Family Physician. Clinical Quality*, *31*(3), 1–5.

Holbrook, M. B., & Corfman, K. P. (1985). Quality and value in the consumption experience: Phaedrus rides again. *Perceived Quality*, *31*(2), 31–57.

Howard, J. A., & Sheth, J. N. (1969). The theory of buyer behavior. *New York*, *63*, 145.

Howlett, M., Kekez, A., & Poocharoen, O. (2017). Understanding Co-Production as a Policy Tool: Integrating New Public Governance and Comparative Policy Theory. *Journal of Comparative Policy Analysis: Research and Practice*, *19*, 1–15. https://doi.org/10.1080/13876988.2017.1287445

Huntington, D., & Schuler, S. R. (1993). The simulated client method: evaluating client-provider interactions in family planning clinics. *Studies in Family Planning*, 187–193.

Hussein, M., Pavlova, M., Ghalwash, M., & Groot, W. (2021). The impact of hospital accreditation on the quality of healthcare: a systematic literature review. *BMC Health Services Research*, *21*(1), 1–12.

Institute of Medicine. (1990). *Crossing the quality chasm : a new health system for the 21st century*. Washington, D.C. : National Academy Press, [2001] ©2001. https://search.library.wisc.edu/catalog/999916953102121

Iyer, A. (1995). *Women in health care: auxiliary nurse midwives*. Foundation for Research in Community Health.

Johnson, P. A., Lee, T. H., Cook, E. F., Rouan, G. W., & Goldman, L. (1993). Effect of race on the presentation and management of patients with acute chest pain. *Annals of Internal*

Medicine, *118*(8), 593–601.

Joss, R., & Kogan, M. (1995). *Advancing quality: Total quality management in the National Health Service*. Open university press.

Juran, J. M. (1999). How to think about quality. *JM Juran, AB Godfrey, RE Hoogstoel, and EG, Schilling (Eds.): Quality-Control Handbook. New York: McGraw-Hill*.

Kahn, K. L., Pearson, M. L., Harrison, E. R., Desmond, K. A., Rogers, W. H., Rubenstein, L. V, Brook, R. H., & Keeler, E. B. (1994). Health care for black and poor hospitalized Medicare patients. *Jama*, *271*(15), 1169–1174.

Kannel, W. B., & Abbott, R. D. (1984). Incidence and prognosis of unrecognized myocardial infarction: an update on the Framingham study. *New England Journal of Medicine*, *311*(18), 1144–1147.

Kjellstrand, C. M. (1988). Age, sex, and race inequality in renal transplantation. *Archives of Internal Medicine*, *148*(6), 1305–1309.

Klabunde, C. N., Potosky, A. L., Harlan, L. C., & Kramer, B. S. (1998). Trends and black/white differences in treatment for nonmetastatic prostate cancer. *Medical Care*, 1337–1348.

Kogan, M. D., Kotelchuck, M., & Johnson, S. (1993). Racial differences in late prenatal care visits. *Journal of Perinatology*, *13*(1), 14–21.

Korsch, B. M., Gozzi, E. K., & Francis, V. (1968). Gaps in doctor-patient communication: I. Doctor-patient interaction and patient satisfaction. *Pediatrics*, *42*(5), 855–871.

Lachman, P., & Nelson, E. C. (2021). Policy, accreditation and leadership: creating the conditions for effective coproduction of health, healthcare and science. *International Journal for Quality in Health Care*, *33*(Supplement_2), ii1–ii3.

Lannin, D. R., Mathews, H. F., Mitchell, J., Swanson, M. S., Swanson, F. H., & Edwards, M. S. (1998). Influence of socioeconomic and cultural factors on racial differences in late-stage presentation of breast cancer. *Jama*, *279*(22), 1801–1807.

Lannon, C., Brack, V., Stuart, J., Caplow, M., McNeill, A., Bordley, W. C., & Margolis, P. (1995). What mothers say about why poor children fall behind on immunizations: a summary of focus groups in North Carolina. *Archives of Pediatrics & Adolescent Medicine*, *149*(10), 1070–1075.

Lantz, P. M., House, J. S., Lepkowski, J. M., Williams, D. R., Mero, R. P., & Chen, J. (1998). Socioeconomic Factors, Health Behaviors, and MortalityResults From a Nationally Representative Prospective Study of US Adults. *JAMA*, *279*(21), 1703–1708. https://doi.org/10.1001/jama.279.21.1703

Leatherman, S. (2002). Applying performance indicators to health system improvement. *Measuring Up*.

Leatherman, S., & McCarthy, D. (1999). Public disclosure of health care performance reports:

experience, evidence and issues for policy. *International Journal for Quality in Health Care*, *11*(2), 93–98.

Lee, T., & Mills, M. E. (2000). Analysis of patient profile in predicting home care resource utilization and outcomes. *JONA: The Journal of Nursing Administration*, *30*(2), 67–75.

Lilford, R., Mohammed, M. A., Spiegelhalter, D., & Thomson, R. (2004). Use and misuse of process and outcome data in managing performance of acute medical care: avoiding institutional stigma. *The Lancet*, *363*(9415), 1147–1154.

Litvack, J. I., & Bodart, C. (1993). User fees plus quality equals improved access to health care: results of a field experiment in Cameroon. *Social Science & Medicine*, *37*(3), 369–383.

Locker, D., & Dunt, D. (1978). Theoretical and methodological issues in sociological studies of consumer satisfaction with medical care. *Social Science & Medicine. Part A: Medical Psychology & Medical Sociology*, *12*, 283–292.

Madan, T. N., Madan, T. N., Wiebe, P., Said, R., & Dias, M. (1980). *Doctors and Society: Three Asian Case Studies: India, Malaysia, Sri Lanka*. Vikas Publishing House Private.

Mainz, J. (2003). Defining and classifying clinical indicators for quality improvement. *International Journal for Quality in Health Care*, *15*(6), 523–530.

Mainz, J., Kristensen, S., & Roe, D. (2022). The power of the patient's voice in the modern health care system. In *International Journal for Quality in Health Care* (Vol. 34, Issue Supplement_1, pp. ii1–ii2). Oxford University Press UK.

Mansour, W., Boyd, A., & Walshe, K. (2020). The development of hospital accreditation in low- and middle-income countries: a literature review. *Health Policy and Planning*, *35*(6), 684–700.

Maxwell, R. J. (1984). Quality assessment in health. *British Medical Journal (Clinical Research Ed.)*, *288*(6428), 1470.

McDonald, D. D., & Gary Bridge, R. (1991). Gender stereotyping and nursing care. *Research in Nursing & Health*, *14*(5), 373–378.

McDonald, T. P., & Coburn, A. F. (1988). Predictors of prenatal care utilization. *Social Science & Medicine*, *27*(2), 167–172.

McFarlane, M. J., Feinstein, A. R., & Wells, C. K. (1986). Necropsy evidence of detection bias in the diagnosis of lung cancer. *Archives of Internal Medicine*, *146*(9), 1695–1698.

McIver, S. (1991). *Obtaining the views of users of mental health services*. King's Fund Centre for Health Services Development.

Mcloughlin, V., Leatherman, S., Fletcher, M., & Owen, J. W. (2001). Improving performance using indicators. Recent experiences in the United States, the United Kingdom, and Australia. *International Journal for Quality in Health Care*, *13*(6), 455–462.

Meredith, P., & Wood, C. (1994). Patient satisfaction with surgical services-Report of the

development of an audit instrument (1991-1993). *Surgical Audit Unit, The Royal College of Surgeons of England*.

Mooney, G. (2000). Judging goodness must come before judging quality–but what is the good of health care? *International Journal for Quality in Health Care*, *12*(5), 389–394.

Moore, R. D., Stanton, D., Gopalan, R., & Chaisson, R. E. (1994). Racial differences in the use of drug therapy for HIV disease in an urban community. *New England Journal of Medicine*, *330*(11), 763–768.

Mosadeghrad, A. M. (2012). A conceptual framework for quality of care. *Materia Socio-Medica*, *24*(4), 251.

National Expert Advisory Group on Safety and Quality in Australian Health Care. (1999). *Implementing safety and quality enchancement in health care: National actions to support quality and safety improvment in Asutralian health care*. https://www.safetyandquality.gov.au/sites/default/files/migrated/final_fullrep.pdf

National Quality Measures Clearinghouse™. (n.d.). *Agency for Healthcare Research and Quality*. US Department of Health and Human Services.

Navarro, V. (2001). The new conventional wisdom: an evaluation of the WHO report health systems: improving performance. *International Journal of Health Services*, *31*(1), 23–33.

Nelson, E. C., Dixon-Woods, M., Batalden, P. B., Homa, K., Van Citters, A. D., Morgan, T. S., Eftimovska, E., Fisher, E. S., Ovretveit, J., & Harrison, W. (2016). Patient focused registries can improve health, care, and science. *Bmj*, *354*.

Newacheck, P. W., Hughes, D. C., & Stoddard, J. J. (1996). Children's access to primary care: differences by race, income, and insurance status. *Pediatrics*, *97*(1), 26–32.

NHS Executive. (1996). *Clinical Audit in NHS*. Department of Health.

Oddone, E. Z., Horner, R. D., Diers, T., Lipscomb, J., Mcintyre, L., Cauffman, C., Whittle, J., Passman, L. J., Kroupa, L., & Heaney, R. (1998). Understanding racial variation in the use of carotid endarterectomy: the role of aversion to surgery. *Journal of the National Medical Association*, *90*(1), 25.

Oliver, R. L. (1981). Measurement and evaluation of satisfaction processes in retail settings. *Journal of Retailing*.

Olshavsky, R. W. (1985). Perceived quality in consumer decision making: an integrated theoretical perspective. *Perceived Quality*, *4*(1), 3–29.

Omoigui, N. A., Miller, D. P., Brown, K. J., Annan, K., Cosgrove III, D., Lytle, B., Loop, F., & Topol, E. J. (1996). Outmigration for coronary bypass surgery in an era of public dissemination of clinical outcomes. *Circulation*, *93*(1), 27–33.

Organization, W. H. (2018). *Handbook for national quality policy and strategy: a practical approach for developing policy and strategy to improve quality of care*.

Ovretveit, J. (1992). *Health service quality: an introduction to quality methods for health services*. Blackwell Scientific.

Øvretveit, J. (2001). Quality evaluation and indicator comparison in health care. *The International Journal of Health Planning and Management*, *16*(3), 229–241.

Panteli, D., Quentin, W., & Busse, R. (2019). Understanding healthcare quality strategies: a five-lens framework. *Improving Healthcare Quality in Europe*, 19.

Parasuraman, A., Zeithaml, V. A., & Berry, L. (1988). SERVQUAL: A multiple-item scale for measuring consumer perceptions of service quality. *1988*, *64*(1), 12–40.

Parasuraman, A., Zeithaml, V. A., & Berry, L. L. (1985). A conceptual model of service quality and its implications for future research. *Journal of Marketing*, *49*(4), 41–50.

Penchansky, R., & Thomas, J. W. (1981). The concept of access: definition and relationship to consumer satisfaction. *Medical Care*, 127–140.

Perloff, J. D., Kletke, P. R., Fossett, J. W., & Banks, S. (1997). Medicaid participation among urban primary care physicians. *Medical Care*, 142–157.

Peterson, E. D., Wright, S. M., Daley, J., & Thibault, G. E. (1994). Racial variation in cardiac procedure use and survival following acute myocardial infarction in the Department of Veterans Affairs. *Jama*, *271*(15), 1175–1180.

Pincus, T., Esther, R., DeWalt, D. A., & Callahan, L. F. (1998). Social conditions and self-management are more powerful determinants of health than access to care. *Annals of Internal Medicine*, *129*(5), 406–411.

Pittman, P., & Hartigan, P. (1996). Gender inequity: an issue for quality assessment researchers and managers. *Health Care for Women International*, *17*(5), 469–486.

Pollitt, C. (1988). Bringing consumers into performance measurement: concepts, consequences and constraints. *Policy & Politics*, *16*(2), 77–87.

Potosky, A. L., Breen, N., Graubard, B. I., & Parsons, P. E. (1998). The association between health care coverage and the use of cancer screening tests: results from the 1992 National Health Interview Survey. *Medical Care*, 257–270.

Priya, R. (1995). Datils Perceptions of Health. *Seminar*, *428*, 15–19.

Priya, R. (2012). AYUSH and public health: democratic pluralism and the quality of health services. *Medical Pluralism in Contemporary India*, 103–128.

Priya, R. (2022). Traditional Medicine in Global Health Systems Approaches: A Review that Calls for Drafting of a PHC 2.0. *Traditional Medicine Review*, *2*(2), 3–15.

Priya, R. M. D. (2007). Health perception Studies and their role in public health policy and planning: Some theoretical and methodological issues. In *Working paper for the 'ublic Report on Health* (p. 21). Council for Social Development.

Pronovost, P. J., Nolan, T., Zeger, S., Miller, M., & Rubin, H. (2004). How can clinicians measure safety and quality in acute care? *The Lancet*, *363*(9414), 1061–1067.

Quadeer, I. (1985). Social dynamics of health care: the CHW scheme in Shahdol District. *Social Health Review*, 74–83.

Quentin, W., Partanen, V.-M., Brownwood, I., & Klazinga, N. (2019). Measuring healthcare quality. *Improving Healthcare Quality in Europe*, 31.

Radl-Karimi, C., Nicolaisen, A., Sodemann, M., Batalden, P., & von Plessen, C. (2020). Under what circumstances can immigrant patients and healthcare professionals co-produce health?-an interpretive scoping review. *International Journal of Qualitative Studies on Health and Well-Being*, *15*(1), 1838052.

Raine, R. (2000). Does gender bias exist in the use of specialist health care? *Journal of Health Services Research & Policy*, *5*(4), 237–249.

Ramayya, Darokar S., R. T. B. and S. M. (2007). *Study of socio-economic, educational and cultural progress of Matang community in Maharashtra*.

Rao, M. (2005). Supreme Court judgement on sterilisations. *Indian J Med Ethics*.

Rathore, S. S., Berger, A. K., Weinfurt, K. P., Feinleib, M., Oetgen, W. J., Gersh, B. J., & Schulman, K. A. (2000). Race, sex, poverty, and the medical treatment of acute myocardial infarction in the elderly. *Circulation*, *102*(6), 642–648.

Reed, J. E., & Card, A. J. (2016). The problem with plan-do-study-act cycles. *BMJ Quality & Safety*, *25*(3), 147–152.

Reilly, T., Meyer, G., Zema, C., Crofton, C., Larson, D., Darby, C., & Crosson, K. (2002). Providing performance information for consumers: experience from the United States. *Measuring Up, Improving Health System Performance in OECD Countries*.

Roe, D., Slade, M., & Jones, N. (2022). The utility of patient-reported outcome measures in mental health. *World Psychiatry*, *21*(1), 56.

Roemer, M. I., Montoya-Aguilar, C., & Organization, W. H. (1988). *Quality assessment and assurance in primary health care*. World Health Organization.

Romano, P. S., Campa, D. R., & Rainwater, J. A. (1997). Elective cervical discectomy in California: postoperative in-hospital complications and their risk factors. *Spine*, *22*(22), 2677–2692.

Russel, R. V, & Hiralal, T. (1916). *Castes of Central Provinces of India*. London.

Sale, D. N. T. (2005). *Understanding clinical governance and quality assurance: Making it happen*. Palgrave Macmillan.

Schulman, K. A., Berlin, J. A., Harless, W., Kerner, J. F., Sistrunk, S., Gersh, B. J., Dube, R., Taleghani, C. K., Burke, J. E., & Williams, S. (1999). The effect of race and sex on physicians' recommendations for cardiac catheterization. *New England Journal of*

Medicine, *340*(8), 618–626.

Scott, A., & Smith, R. D. (1994). Keeping the customer satisfied: issues in the interpretation and use of patient satisfaction surveys. *International Journal for Quality in Health Care*, *6*(4), 353–359.

Sen, A. (1992). *Inequality Re-Examined; Russell Sage Foundation and Clarendon Press: New York, NY, USA*. Oxford, UK.

Shavers, V. L., & Brown, M. L. (2002). Racial and ethnic disparities in the receipt of cancer treatment. *Journal of the National Cancer Institute*, *94*(5), 334–357.

Singh, K. S. (2004). *People of India: Maharashtra, Vol. 3 Part 2*. Populat Prakashan.

Siraj-ul-Hassan, S. (1920). *The castes and Tribes of HEH the Nizam's Dominions*. Dalcassian Publishing Company.

Sirey, J. A., Meyers, B. S., Bruce, M. L., Alexopoulos, G. S., Perlick, D. A., & Raue, P. (1999). Predictors of antidepressant prescription and early use among depressed outpatients. *American Journal of Psychiatry*, *156*(5), 690–696.

Sirio, C. A., Shepardson, L. B., Rotondi, A. J., Cooper, G. S., Angus, D. C., Harper, D. L., & Rosenthal, G. E. (1999). Community-wide assessment of intensive care outcomes using a physiologically based prognostic measure: implications for critical care delivery from Cleveland Health Quality Choice. *Chest*, *115*(3), 793–801.

Sitzia, J. (1999). How valid and reliable are patient satisfaction data? An analysis of 195 studies. *International Journal for Quality in Health Care*, *11*(4), 319–328.

Sorlie, P. D., Backlund, E., & Keller, J. B. (1995). US mortality by economic, demographic, and social characteristics: the National Longitudinal Mortality Study. *American Journal of Public Health*, *85*(7), 949–956.

Stafford, R. S., Sullivan, S. D., & Gardner, L. B. (1993). Trends in cesarean section use in California, 1983 to 1990. *American Journal of Obstetrics and Gynecology*, *168*(4), 1297–1302.

Swensen, S. J., Meyer, G. S., Nelson, E. C., Hunt, G. C., Pryor, D. B., Weissberg, J. I., Kaplan, G. S., Daley, J., Yates, G. R., & Chassin, M. R. (2010). Cottage industry to postindustrial care the revolution in health care delivery. *New England Journal of Medicine*, *362*(5), e12.

Tabish, S. A. (2001). *Hospital and health services administration: principles and practice*. Oxford University Press, USA.

Taylor, M. J., McNicholas, C., Nicolay, C., Darzi, A., Bell, D., & Reed, J. E. (2014). Systematic review of the application of the plan–do–study–act method to improve quality in healthcare. *BMJ Quality & Safety*, *23*(4), 290–298.

The Department of Health. (1997). *The new NHS modern .dependable*. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_dat

a/file/266003/newnhs.pdf

The Department of Health. (1998). *A First Class Service: Quality in National Health Service*.

The Department of Health. (2001). *NHS Performance Indicators: A Consultation*.

The Hindu. (2005, July 31). Another Honour for Apollo. *The Hindu*.

Thier, S. O., & Gelijns, A. C. (1998). Perspective: Improving Health: The Reason Performance Measurement Matters: To advance quality measurement, we must bring providers' and patients' views to the table. *Health Affairs*, *17*(4), 26–28.

Thomas, J. W., & Hofer, T. P. (1998). Research evidence on the validity of risk-adjusted mortality rate as a measure of hospital quality of care. *Medical Care Research and Review*, *55*(4), 371–404.

Thomas, L. R., Fox, S. A., Leake, B. G., & Roetzheim, R. G. (1997). The effects of health beliefs on screening mammography utilization among a diverse sample of older women. *Women & Health*, *24*(3), 77–94.

Tobin, J. N., Wassertheil-Smoller, S., Wexler, J. P., Steingart, R. M., Budner, N., Lense, L., & Wachspress, J. (1987). Sex bias in considering coronary bypass surgery. *Annals of Internal Medicine*, *107*(1), 19–25.

TQA Research. (1993). *Patient satisfaction in NSW public hospitals: Summary*.

Uggerby, C., Kristensen, S., Mackenhauer, J., Knudsen, S. V., Bartels, P., Johnsen, S. P., & Mainz, J. (2021). From accreditation to quality improvement—The Danish National Quality Programme. *International Journal for Quality in Health Care*, *33*(2), mzab071.

Van Ryn, M., & Burke, J. (2000). The effect of patient race and socio-economic status on physicians' perceptions of patients. *Social Science & Medicine*, *50*(6), 813–828.

Virnig, B. A., Lurie, N., Huang, Z., Musgrave, D., McBean, A. M., & Dowd, B. (2002). Racial variation in quality of care among Medicare+ Choice enrollees. *Health Affairs*, *21*(6), 224–230.

Vlassoff, C. (1994). Gender inequalities in health in the third world: uncharted ground. *Social Science & Medicine*, *39*(9), 1249–1259.

Wallen, J., Waitzkin, H., & Stoeckle, J. (1979). Physician stereotypes about female health and illness: A study of patient's sex and the informative process during medical interviews. *Women & Health*, *4*(2), 135–146.

Wallston, B. S., DeVellis, B. M., & Wallston, K. (1983). Licensed practical nurses' sex role stereotypes. *Psychology of Women Quarterly*, *7*(3), 199–208.

Walsh, M. (2018). Towards critical quality. In *Managing quality: Strategic issues in health care management* (pp. 41–55). Routledge.

Welfare, A. I. of H. and. (1999). *Australia's welfare: services and assistance*. Australian Institute

of Health and Welfare.

Wensing, M., Grol, R., & Smits, A. (1994). Quality judgements by patients on general practice care: a literature analysis. *Social Science & Medicine*, *38*(1), 45–53.

Werner, R. M., & Asch, D. A. (2005). The unintended consequences of publicly reporting quality information. *Jama*, *293*(10), 1239–1244.

Whittle, J., Conigliaro, J., Good, C. B., & Joswiak, M. (1997). Do patient preferences contribute to racial differences in cardiovascular procedure use? *Journal of General Internal Medicine*, *12*(5), 267–273.

Whittle, J., Conigliaro, J., Good, C. B., & Lofgren, R. P. (1993). Racial differences in the use of invasive cardiovascular procedures in the Department of Veterans Affairs medical system. *New England Journal of Medicine*, *329*(9), 621–627.

Williams, B. (1994). Patient satisfaction: a valid concept? *Social Science & Medicine*, *38*(4), 509–516.

World Health Organization. (2004). *Quality improvement in primary health care: a practical guide*.

World Health Organization. (2008). *Guidance on developing quality and safety strategies with a health system approach (No. WHO/EURO: 2008-3958-43717-61500)*.

Yang, H. (2007). Building a conceptual framework for quality of care. *Chinese Health Quality Management*, *14*(1), 1–9.

Zeithaml, V. A. (1987). *Defining and relating price, perceived quality, and perceived value*. na.